Sowing Seeds in the Mountains

Community-Based Coalitions for Cancer Prevention and Control

NATIONAL INSTITUTES OF HEALTH
National Cancer Institute

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Sowing Seeds in the Mountains

Community-Based Coalitions for Cancer Prevention and Control

Edited by
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The Appalachia Leadership Initiative on Cancer (ALIC)
Cancer Control Sciences Program
Division of Cancer Prevention and Control
National Cancer Institute

The Appalachian Region

1990 population, 20.7 million

Sowing Seeds in the Mountains

Community-Based Coalitions for Cancer Prevention and Control

Additional Resources

Southern Appalachia Leadership Initiative on Cancer (SALIC)

The phone number for SALIC is (919) 515-2770.

Liaison Office for Cancer Communications
National Cancer Institute
Building 31 10A16
9000 Rockville Pike
Bethesda, Maryland 20892

The National Cancer Institute (NCI) recently established the Liaison Office for Cancer Communications. Its mission is to communicate and cooperate with advocacy and voluntary organizations concerned with cancer to promote the common goal of cancer prevention, detection, treatment, and quality of life of cancer survivors and participants in clinical trials. The Office, which is part of NCI's Office of Cancer Communications (OCC), serves as a key point of contact and interaction with the leadership of national advocacy and voluntary organizations. It coordinates information on NCI-wide activities and programs of interest to these groups; exchanges and disseminates information; and facilitates collaborative efforts. The Liaison Office seeks to understand the needs and capabilities of these groups and to strengthen NCI relationships and cooperation with them as important constituents. The Office supports OCC/NCI's priority programs and increases their reach, acting as a partner and bridge to these important communities. National organizations are encouraged to share NCI information with their regional and local memberships through meetings, newsletters and other channels. Information on how to contact many national cancer advocacy and voluntary organizations which may have regional and local memberships is available from the Liaison Office at the address listed above.

The following groups provide information on community organizing, support, and advocacy concerning breast cancer:

Breast Cancer Action
1280 Columbus Avenue
Suite 204
San Francisco, CA 94133
(415) 922-8279

Living Beyond Breast Cancer
P.O. Box 92
Narberth, PA 19072
(610) 668-1320

National Breast Cancer Coalition
1707 L Street, N.W.
Washington, DC 20036
(202) 296-7477

Virginia Breast Cancer Foundation
P.O. Box 17884
Richmond, VA 23226
(804) 285-1200
(800) 345-8223

Women of Color Breast Cancer Survivor's Support Project
8610 So. Sepulveda Boulevard
Los Angeles, CA 90045
(310) 216-3200

Women's Cancer Resource Center
3923 Shattuck
Berkeley, CA 94705
Information Referral Hotline (510) 548-9272
Business Office (510) 548-9286

Women's Community Cancer Project of Cambridge/Boston
c/o The Women's Center
46 Pleasant Street
Cambridge, MA 02139
(617) 354-9888

The National Cancer Institute. NIH Publication No. 94-3779, September 1994.

FOREWORD

The National Cancer Institute (NCI) has long been committed to improving cancer rates among populations with special needs, including groups that have high cancer rates and those that are underserved because they lack access to adequate cancer prevention and control services. Since 1986, the Institute has supported outreach initiatives that target these special populations. The National Black Leadership Initiative on Cancer, the National Hispanic Leadership Initiative on Cancer, and the Appalachia Leadership Initiative on Cancer (ALIC) all seek to involve lay and professional leaders in cancer prevention and control activities at the grassroots, state, regional, and national levels. NCI believes that this approach is an invaluable aid in defining the problem of cancer in special populations, developing appropriate and relevant outreach activities and materials, and developing a sustainable network that will continue to involve key actors in cancer prevention and control and to provide needed state-of-the-art cancer information to targeted groups.

In September 1992, NCI made awards to institutions located within the 13 Appalachian states to develop and implement four ALIC projects. These projects are focusing initial attention on those areas of Appalachia most in need of cancer prevention and control outreach activities—namely, rural and medically underserved communities.

This monograph is the first fruit of ALIC's effort to reduce cancer incidence and mortality and to improve cancer survival rates in Appalachia. This comprehensive volume is the product of collaboration among the staff members of four ALIC projects and experts in fields such as theories concerning coalition building, the social and economic history of Appalachia, and health status and health care in the region. This approach has helped ensure that the monograph reflects the culture and information needs of its intended audiences, which include coalition members, health care professionals, community and media representatives, and other key leaders in Appalachia. At the same time, participating NCI and ALIC project staff have gleaned insights and shared ideas that will help them plan and implement ALIC cancer control activities more effectively.

Prepared during the first year of planning for the ALIC projects, *Sowing Seeds in the Mountains* already has begun the work described in its title. The collaborative process of developing the monograph has helped foster new linkages among key players in Appalachia, such as local medical centers and Cooperative Extension Service offices. This monograph presents new data on Appalachia that will be invaluable to health promotion and disease prevention efforts in the region. Several chapters also identify important gaps in existing data and serve to

stimulate efforts by ALIC projects as well as by state and federal agencies to collect data that will fill some of these gaps. The selection of contributors and reviewers has helped identify experts with an abiding interest in the region, including those concerned with Appalachian culture and political economy; rural and community health; community leadership, organizing, and development; and community-based health promotion programs. The quilts and photographs that illustrate the volume celebrate the talents and cultural heritage of the region.

The primary purpose of the monograph is to provide background material that will make prospective ALIC coalition members and informed laypersons more effective participants and leaders. However, the monograph development process, as described in Appendix C, also provides a model of participatory research and collaboration for other policy issues and program areas. In addition, the monograph will serve as a baseline for ALIC and a prospective statement of needs in Appalachia as well as the program's opportunities and problems. It is hoped that the monograph will be revised at the end of the 5-year project period to reflect lessons learned as part of the ALIC experience.

We look forward to the contributions that ALIC will make to the evolution of community-based health promotion and disease prevention strategies and to the prevention and control of cancer in Appalachia.

Samuel Broder, M.D.
Director
National Cancer Institute

PREFACE

Although the mandate to conduct cancer control activities has existed since the founding of the National Cancer Institute (NCI) in 1937, the Institute's focus on cancer prevention and control has evolved with advances in the basic and clinical understanding of the nature, causes, and treatment of cancer. Studies indicating that lifestyle and environmental factors contribute to the development of cancer and that early detection of the disease could increase chances for survival have supported the concept of cancer as a preventable and controllable disease. The National Cancer Act of 1971 designated funding for the diffusion and transfer of new research information into practice and authorized new cancer centers to conduct cancer demonstration and outreach programs. Thus, developmental research emerged as a key element in the cancer control effort, and a renewed emphasis was placed on the rapid dissemination of cancer research results to local communities.

A milestone in the development of a cancer control research process occurred in 1982, when NCI's Division of Cancer Prevention and Control (DCPC) conducted a comprehensive review of cancer control activities with the goal of developing a national strategy for cancer prevention and control. Beginning with a consensus definition of cancer control, DCPC established a scientific logic for cancer control research that progresses from basic investigations to broad applications in target populations. According to DCPC's definition, cancer control must involve interventions that can be tested for their applicability to defined populations. The five sequential phases of cancer control research ensure that an adequate science base precedes intervention efforts and that research and intervention programs are mutually reinforcing. This definition and systematic approach to cancer control are described in Chapter 9 of this monograph.

Some of the earliest studies illustrating the last two phases of cancer control research—studies in defined populations (phase IV) and demonstration and implementation in large populations (phase V)—focused on the control of smoking and other tobacco use. NCI's Community Intervention Trial for Smoking Cessation (COMMIT) and American Stop Smoking Intervention Study for Cancer Prevention (ASSIST) were designed to test community-based interventions for reducing tobacco use. NCI also recognized the need for local participation in cancer control interventions among minority populations and medically underserved groups. Consequently, the Institute developed collaborative programs with experienced organizations capable of reaching these groups in local communities. The Appalachia Leadership Initiative on Cancer (ALIC) is one of three NCI-supported leadership initiative programs designed to help reduce cancer incidence and mortality and to improve cancer survival by identifying

community leaders who will build a network of coalitions to support programs that reflect state-of-the-art knowledge concerning cancer prevention and control.

The networks supported by ALIC and the other two leadership initiatives have the potential for lasting effects on cancer control in their target communities. By disseminating culturally appropriate messages that stress the importance of early detection and prevention, ALIC can increase awareness about measures that can reduce the risk of developing cancer and increase the risk of surviving the disease. This improvement could be a critical factor in controlling cancer in Appalachian populations, which limited data indicate may have higher rates of tobacco use and lower rates of cancer screening than populations living outside the region. By mobilizing and increasing coordination among influential actors in cancer control and by enhancing leadership skills among Appalachian populations, ALIC has the potential to help institutionalize local, state, and regional support for cancer prevention and control activities. Such ongoing support would help maximize the limited resources available in the region. The demands of ALIC project planning and evaluation will stimulate the collection of data needed to address gaps in our knowledge of cancer and related health issues in Appalachia.

Another important role of networks supported by programs such as ALIC is to provide feedback that will help NCI develop and prioritize initiatives for cancer control research. ALIC projects are forming alliances to share data with established cancer registries in Appalachian states and to help establish tumor registries for Appalachian areas of states where no data on the incidence of cancer currently exist. These data, along with information concerning risk behaviors as well as workplace and environmental exposures in Appalachia, will help delineate the problem of cancer in the region and perhaps shed light on related issues in other rural, economically distressed, and medically underserved areas. ALIC projects will help further our knowledge about developing community-based cancer control coalitions as well as designing successful strategies for cancer control intervention.

Programs such as ALIC constitute an important component of cancer prevention and control. While biomedical researchers work to expand our understanding of the causes, natural history, and treatment of cancer, NCI's leadership initiatives seek to involve informed and concerned individuals and organizations in improving the health of their communities. *Healthy People 2000*, a comprehensive blueprint for health promotion and disease prevention, acknowledges that one of the primary challenges of this national effort is to combine the strength of scientific knowledge, professional skill, individual commitment, and community support in efforts to improve the public health. ALIC has the potential to achieve this goal.

This monograph represents a year of planning and collaboration by ALIC project staff as well as key actors in Appalachia and in the field of cancer control. It is hoped that, during the next four years of the program, ALIC will continue to build new partnerships, fortify and expand existing resources, and stimulate community outreach efforts on behalf of cancer prevention and control in Appalachia.

Peter G. Greenwald, M.D.
Director
Division of Cancer Prevention and Control

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INTRODUCTION

Richard A. Couto

Cancer is so common an illness among Americans that an estimated one in three Americans now living will have cancer in their lifetimes. Cancer is not one disease but a constellation of more than 100 different diseases, each characterized by the uncontrolled growth and spread of abnormal cells (U.S. Department of Health and Human Services 1991). In some cancers, abnormal cells eventually may proliferate sufficiently to interfere with some vital function of a body organ and produce death. Cancer is costly as well as common. In 1982, cancer cost an estimated $72.5 billion (Rice et al. 1985). Cancer is also preventable. We can reduce the risk for many of the more than 1 million new cases of cancer that occur annually. For these reasons, cancer is a target for disease prevention and health promotion. This monograph examines the Appalachia Leadership Initiative on Cancer (ALIC) and its plan to prevent cancer and promote health.

Disease prevention requires social change. Social change requires the participation and commitment of those for whom the change is intended. Thus, the process and purpose of ALIC center on the creation of community coalitions. This monograph provides background information, rationale, and methods related to creating and maintaining community coalitions to reduce the risk of cancer among residents of the Appalachian region. It offers information on community coalitions from an array of perspectives and activities within cancer prevention and control efforts. The monograph also offers an overview of the context in which this work takes place. It describes related efforts to effect social change in the Appalachian region and elsewhere as well as specific experience with other cancer prevention programs.

The American Health Care Crisis

Although specific to the Appalachian region, ALIC addresses national problems. For example, perhaps no word is used more often in describing the American health care system than "crisis." The three measures that we ordinarily use to assess a health care system—access, cost, and quality—all seem to be in an unsatisfactory state. An increasing number of Americans, estimated in 1992 at 35 million, have no medical insurance (*Wall Street Journal* 1992). This financial barrier to accessing health care is compounded by another barrier, a paucity of health care providers in many rural and urban areas. The cost of health care has spiraled. It has increased faster than 10 percent annually from 1987 to 1991. In 1970, we spent $74.4 billion or $346 per American on health care. Twenty years later, we spent $675 billion or $2,601 per person (Boring et al. 1991). Despite these huge sums and increased spending, Americans lag behind comparable industrial nations in most measures of well-being. Indeed, statistics on infant

mortality from our inner cities shamefully lag behind the measures of some developing nations.

The American health care system is in crisis because these unsatisfactory measures are related. More and more Americans are without medical insurance because the increased costs of medical care drive up the cost of insurance premiums and more employers either withdraw medical insurance as part of their employees' benefit package or curtail the coverage they provide. One of the many factors fueling the increased costs of medical care is the heavy reliance on expensive, advanced technologies to treat diseases. In barest outline, our health care crisis entails a sophisticated drug- and hospital-based system of illness treatment that has stretched the capacity of the American people, businesses, and government to finance.

The sense of crisis has stimulated searches for solutions, including less expensive interventions to prevent illness. Many of the conditions by which we measure health can be improved without costly medical interventions. Adequate prenatal care, for example, reduces the risk of low birth weights, their complications, and their attendant medical and human costs. Similarly, low-fat diets, exercise, and tobacco abstinence can reduce personal risk for debilitating illness and financial risk for extensive medical care. These are some of the reasons for the current emphasis on disease prevention and health promotion.

The effectiveness of these preventive and promotional measures depends on reaching those individuals who run the greatest risk for unnecessary illness and premature mortality. ALIC proposes to reach one set of people at risk for preventable cancer. In these efforts, ALIC is part of a national effort to improve the health of all Americans, to reduce the costs of unnecessary illness, and to reduce the number of expensive treatments for illness. This monograph provides background and a starting point for ALIC.

ALIC Background

ALIC is a new initiative of the longstanding commitment of the National Cancer Institute to prevent and control cancer. Studies have shown that some groups have higher rates and risks of cancer than others. Consequently, NCI created several outreach programs to reduce the risks of cancer among specific groups of Americans. The National Black Leadership Initiative on Cancer (NBLIC) was the first, the National Hispanic Leadership Initiative on Cancer was the second, and the Appalachia Leadership Initiative on Cancer is the third.

By 1992, NBLIC had created a network of concerned and active African-American leaders throughout the country to help organize, implement, and support cancer prevention programs at the national and local levels. The Philadelphia NBLIC, for example, played a major role in deterring the R.J. Reynolds Tobacco Company from marketing Uptown cigarettes to African Americans. NBLIC has established 50 community cancer coalitions nationwide, and additional coalitions are being formed. It has directly or indirectly reached 15 to 20 million African Americans, or 50 to 60 percent of the national African-American population. Based on the success of NBLIC, NCI developed a similar initiative for the Hispanic population, starting in 1992.

ALIC differs from these preceding outreach efforts. Proceeding from a geographic definition rather than from racial or ethnic characteristics of a group, ALIC is targeted to the residents of rural areas of the Appalachian region—in particular, the low-income residents of these areas.

Appalachia is largely rural with nearly two-thirds of its 399 counties classified as rural. Thirty-five percent of Appalachian counties are categorized as distressed or severely distressed by the Appalachian Regional Commission based on 1988 measures of per capita income, unemployment, and levels of poverty. Many counties also have shortages of health services. According to the U.S. Health

Resources and Services Administration, more than 85 percent of Appalachian counties contain one or more areas designated medically underserved and more than 65 percent of Appalachian counties contain one or more primary medical care Health Professional Shortage Areas, as Chapter 4 explains.

In selecting Appalachia as a regional target for cancer control, ALIC affirms the long-standing scientific evidence that risk for preventable illness and premature mortality is higher for individuals with low incomes and low levels of education. These characteristics are concentrated among racial and ethnic groups. They also are concentrated in some geographic areas, such as some portions of Appalachia and American inner cities. Although it differs by its geographic focus, ALIC continues the pattern of preceding outreach and leadership initiative programs to target groups at high risk for preventable cancer and avoidable mortality.

ALIC's goals are similar to those of the other outreach efforts of NCI. Specifically, ALIC intends to:

- Reduce cancer incidence and mortality and to improve survival rates in Appalachia;
- Prevent future cancer incidence and mortality rate increases;
- Reduce barriers preventing Appalachians from gaining access to quality cancer control services and referral to appropriate screening, diagnostic, and therapeutic cancer programs; and
- Stimulate greater participation of Appalachians in community cancer control outreach programs.

To achieve these goals, ALIC will establish a structure for the delivery of cancer control outreach activities to Appalachian communities through the work of four projects funded for a 5-year period. Each project's objective will be to:

- Develop, disseminate, and support effective cancer control intervention programs and strategies in Appalachian communities;
- Stimulate participation of Appalachian community leaders (lay and professional) as members of community cancer control coalitions;
- Stimulate cancer control research in Appalachia; and
- Evaluate the effectiveness of this initiative.

Four institutions were awarded cooperative agreements in September 1992 to support and carry out ALIC projects in four areas of Appalachia. Audrey N. Maretzki, Ph.D., professor of food science at Pennsylvania State University, will direct the ALIC project in Appalachian Maryland, New York, and Pennsylvania through the Cooperative Extension Service. Fred R. Butcher, Ph.D., director of the Mary Babb Randolph Cancer Center at West Virginia University, will direct the ALIC project in West Virginia and Appalachian Ohio. Gilbert H. Friedell, M.D., director of cancer control, Lucille Parker Markey Cancer Center at the University of Kentucky Medical Center, will direct the ALIC project in eastern Kentucky, eastern Tennessee, and southwestern Virginia. Finally, Barbara K. Garland, Ph.D., M.P.H., rural health program coordinator for the North Carolina Cooperative Extension Service at North Carolina State University, will direct the ALIC project in Appalachian portions of Georgia, North Carolina, and South Carolina. Each project involves the cooperation of other key actors in cancer control, as explained in Section III. Together, these projects propose to work in 218 of Appalachia's 266 rural counties. Funding for comparable work in Appalachian Alabama and Mississippi is still being sought.

Purpose of this Monograph

The primary purpose of this monograph is to provide prospective coalition members with information about ALIC, the four projects it is supporting, their proposed activities, and principles of effective coalition building. For

example, the effectiveness of community coalitions depends on the informed participation of community leaders. This monograph conveys some of the information that prospective coalition members will need. In addition, policymakers, media representatives, and other participants, who are central to the success of community coalitions, will find useful information on ALIC, Appalachia, the region's health care needs, the context of health promotion and cancer control nationally, and the principles of good practice of community coalition building and action.

This monograph provides a measure of ALIC's starting point. It incorporates statements of the ALIC project staff about the problems they intend to address and how they intend to address them. The first year of the ALIC program is for planning. Consequently, the preliminary statements found in this monograph will change as project staff acquire new information and modify their initial plans accordingly. Thus, this monograph deals with ALIC in a prospective manner. A subsequent report or monograph, developed later in the ALIC program, will provide a retrospective analysis and lessons learned from the individual projects.

The monograph also provides some initial direction for ALIC. The development of the ALIC projects and the monograph has been interactive. Not only have project staff contributed to and reviewed the monograph's chapters, they have met with other chapter contributors and discussed the monograph with other reviewers. In this way, the ideas of the monograph have been integral to the first year of planning for ALIC. Project staff discussed with peer reviewers the content of each chapter. These discussions made clear what the project staff needed and illustrated the problems and prospects of coalition work.

Outline of this Monograph

Section I provides the Appalachian context for ALIC. Chapter 1 provides an introduction to the region. It offers a geographic definition of the region created by the Appalachian Regional Commission (ARC) in 1965, a brief history of other definitions, and a review of studies of Appalachia, including recent interpretations of Appalachian culture. Chapter 2 offers an overview of socioeconomic trends and issues within the region. Although Appalachia often is treated as a region set apart, this chapter relates Appalachia to trends and issues prevalent in the American economy as a whole. Chapter 3 examines indicators of health, morbidity, and mortality in the Appalachian region, including the relative risk of Appalachian residents for some illnesses. Many statistics offered in this chapter were collected and analyzed especially for this monograph and are reported here for the first time. Chapter 4 reports on programmatic reforms in health care and identifies various programs to provide and train health personnel and programs in the region. The chapter also outlines current health needs in Appalachia and the gaps in the health care infrastructure. Chapter 5 distills lessons from the array of community organizing efforts in the region. Appalachia has hosted a range of citizen action groups and community organizations that are exemplary to the nation. Their actions and their lessons provide an important context for community-based coalition programs such as ALIC.

Section II discusses specific elements of the context and precedents of ALIC. Chapter 6 familiarizes readers with the rationale and specifics of a national health promotion strategy expressed in *Healthy People 2000* (U.S. Department of Health and Human Services 1991). It focuses on the objectives and interventions regarding cancer. This chapter also indicates baseline measures for the nation, compared with measures for Appalachia, and the need to improve both sets of measures. Chapter 7 discusses the relation of socioeconomic status and the relative risks of cancer with respect to rural areas of Appalachia.

Chapter 8 discusses the increased emphasis on coalition interventions in health and other programs, the rationale for coalition interventions, some principles of practice, and the particular challenges that rural areas pose for coalition efforts. Chapter 9 goes beyond theory to discuss the practice and lessons of coalition building for health promotion and disease prevention. Outreach programs of NCI, such as the American Stop Smoking Intervention Study for Cancer Prevention (ASSIST), offer valuable lessons in conducting community-based, problemsolving interventions, as this chapter explains. NCI's model of community intervention also is described. Chapter 10 surveys efforts by health care activists to reform health care. In particular, the chapter examines advocacy and activist groups organized around breast and reproductive cancers to describe the ways in which women have become more active consumers of health care and informed participants in health care policy.

Section III presents the plans of each of the four ALIC projects. In particular, these chapters outline the promise of coalition building and the problems of cancer within the region. Chapters 11 through 14 describe the starting points of the four projects and the strategies and tactics that each ALIC project proposes to achieve the goals and objectives of ALIC.

The monograph concludes with a brief summation of the implicit and explicit principles of good practice in coalition building for health promotion. These principles will serve as premises for the initial stages of ALIC and the methods to be tested and reformulated by its experience.

At the end of each chapter, there is a box containing some lessons and advice for ALIC participants based on the chapter material.

The appendices provide supporting information. Appendices A and B provide a set of measures, frequently referred to in the chapters of Section I, for each Appalachian county. There are occasional modest differences between the values presented in the chapter tables and those in Appendices A and B, due to the use of different data sets. Appendix C describes the process of developing this monograph and may be of special interest to readers who deal with program development and implementation. We offer the valuable lessons we have acquired in our efforts to integrate research and program development. We often realized that in producing this monograph we were replicating the process of coalition building, including its frustrations and rewards. The resources listed in Appendix D offer a selected set of public and private agencies and organizations that are sources of additional information on Appalachia, cancer prevention and control, and other public health issues. Appendix E offers a list of acronyms, and Appendix F explains how urban and rural counties are defined in this monograph.

Problems and Prospects of Community Coalitions

Constructing community coalitions presents several problems, some of which are explicit and others implicit in this monograph. It may be useful for readers to consider that some organization leaders imagine themselves outside the system they intend to change, pulling at the boundaries of that system to stretch it to meet needs and issues that are not covered. Other organization leaders imagine themselves within a system they intend to change and push at the boundaries of that system to stretch it to extend to needs and issues that are not covered. Chapter 9 describes some "push" coalitions within the programs of NCI. Chapters 5 and 10 illustrate coalitions that pull at the boundaries and demand change of those within the system and coalitions that develop alternatives to the system. The prospects for community-based coalitions are enhanced by the common ground on which those pulling and those pushing at the boundaries stand and because they are both working to move the boundaries

in roughly the same direction. The uneven speed at which groups may push or pull the boundaries sometimes creates conflict among the groups. That conflict dissipates the energy that might have gone into moving the boundaries at any speed.

Several problems lie within the prospects of community-based coalitions such as the ALIC projects. First of all, the consensus on grassroots approaches to empowerment conceals many differences among the people who use these terms. Boundary pushers (those within the system) and boundary pullers (those who see themselves as outside the system) generally have different standards for representation and participation of people to be served by change. Boundary pullers are likely to want direct representation and full participation by as many individuals and groups affected by a program as possible. They are likely to examine new programs for their potential to serve as free spaces that develop people as participants in a democratic society, as explained in Chapter 5. Boundary pushers are more willing to settle for indirect representation of affected individuals and groups and for advocacy for them by people deemed capable of speaking for those affected. They are likely to examine new programs for their potential to change, incrementally, institutional practices and programs, as explained in Chapter 9.

Empowerment also is viewed differently by boundary pullers and pushers. For boundary pullers, empowerment probably means some change in resource distribution and power relationships. For boundary pushers, empowerment more likely means advocacy for those in need and changes in professional attitudes but not changes in the power relations embedded in professional roles. The suggestions offered in Chapters 5, 8, and 10 take into account some of the differences likely to be found among coalition members. Chapter 9 suggests that there are differences among members of coalitions and networks of boundary pushers or boundary pullers and not merely between them. These differences simply exacerbate the problems for coalitions that attempt to combine groups of boundary pushers and boundary pullers that differ among themselves. The suggestion embedded in this observation is that coalition organizers and members, whether boundary pushers or boundary pullers, remain mindful of and sensitive to their differences with other groups and among members of those groups.

There are additional problems in attempting to integrate all or even most elements of the chapters of this monograph, just as the elements of a coalition may not always fit. Some chapters emphasize the research nature of ALIC; these are written by people close to NCI who also view ALIC as a bottom-up approach. Other chapters emphasize the service nature of ALIC; these are written by Appalachia watchers who are inclined to explain ALIC as a top-down program. The chapters of Section III straddle these differences with tactics such as action research and participatory research.

Another set of problems for ALIC coalitions relates to what is not known about the condition to be addressed and the resources to use. Large, significant gaps exist in our knowledge about Appalachian health conditions, as Chapter 3 reports, and about the relation of socioeconomic status and cancer, as Chapter 7 explains. These gaps appear in the descriptions of each of the projects in Chapters 11, 12, 13, and 14 and contribute to some initial vagueness about specific intervention strategies, intended outcomes, and evaluation procedures. The ALIC program wisely provided for a year of planning because of these gaps. In addition, ALIC addressed the problem of information with a specific goal to stimulate cancer control data collection and research efforts.

Any program like ALIC also must contend with the problems of what is known about Appalachia, health, and health resources as well what is not known about them. For example, Chapters 1 and 3 explain the errors of some accepted knowledge about Appalachian culture. These chapters and

the others of Section I treat the Appalachian region as a rural area within the overall American economy and health care system. They relate the problems of Appalachia to American issues rather than to characteristics of people in the region. Yet pejorative views of the people of the region abound and are used to explain the conditions of poverty and need in Appalachia. Coalitions are likely to have members with strong and conflicting interpretations about the origins of Appalachian problems. Chapters 1, 3, and 5 warn that conflicting interpretations exist even as they explain the region's needs in political, not personal, terms. On the other hand, the chapters of Section III that explain ALIC projects allay some of the worst fears about a program imposed from a distant place to test some new theory. Although ALIC fits this description in some ways, it is premised on the redeeming belief that local representative coalitions probably know best the economics of the local area and the resources of the local people. The ALIC projects place trust in that local knowledge rather than in a possibly errant, common understanding inappropriately applied to a diverse region with very different communities and needs.

In addition, what we know about socioeconomic status and health may be a problem. As Chapters 6 and 7 explain, we know more about personal behavior risks for cancer and other illnesses. We know that smoking, alcohol consumption, and fatty diets increase risks for illness, including some cancers, and are more prevalent among low-income groups. Based on this knowledge, ALIC project coalitions may be tempted to intervene to change personal behaviors. However, Chapter 7 explains that poverty is an antecedent and background factor for higher rates of illness in general. The relationships of socioeconomic status to several dimensions of health are complicated and cannot be reduced to "one big factor," not even health risk behaviors.

Similarly, we know that socioeconomic status is related to access to health care and that access affects late diagnosis of cancer and contributes to higher cancer mortality rates among poor people. We also know, based on studies reviewed in Chapter 7, that it is not a matter of access alone but also the forms of health care to which people have access that influence their health, including their risks of and treatment for cancer. Consequently, the health care programs described in Chapter 4 would seem as important to ALIC coalition efforts as behavioral changes. Similarly, background factors associated with poverty influence cancer rates. Chapter 7 identifies education, form of employment, nutritional status, living standard, and social support system as factors related to poverty with bearing on the incidence and mortality of cancer.

These systemic factors suggest that changes in the health care system and social welfare policy have direct bearing on cancer among those in poverty, just as health behaviors do. Boundary pullers are more inclined to start with systemic factors—for example, environmental hazards and broad elements of socioeconomic status. Boundary pushers are more likely to begin with more manageable tasks that are more immediately related to specific goals of risk reduction and illness prevention and control—for example, adapting printed materials to the appropriate literacy level of a target group. Boundary pullers are inclined to focus on factors over which an individual has little or no control rather than on individual behaviors and to seek changes in systems and the environment that impinge on health and individual control over it. Boundary pushers are inclined to apply personal responsibility for health and to insist on the need for behavioral change as well as systemic change. These differences are foreseeable problems for coalition organization and maintenance.

There is much common ground here and, consequently, hope for success. For example, increased access to health resources probably will offer all coalition members a mutually agreed-on goal. Chapter 4 addresses the problem of health resources in the Appalachian

region. Chapter 5 points out organized efforts to address background issues in Appalachia. Chapter 7 suggests how the lack of access to health care resources may affect cancer incidence and mortality. Chapter 8 points out a plethora of community-based coalitions in a wide variety of problem settings. Chapter 9 describes programs within NCI to make more and better resources available to prevent and control cancer. Chapter 10 suggests how people have protested the lack of adequate resources and developed needed resources specific to cancer. These chapters suggest that agreement on the nature of the problem to be addressed is itself a problem. It is a problem that ALIC projects intend to address in their first year, as Chapters 11, 12, 13, and 14 explain.

Conclusion

If the solutions to resolve America's health care crisis, or the part of it that cancer represents, were apparent, undoubtedly we would have applied them already. Likewise, if we knew how to end the chronic poverty of some parts of the Appalachian region and its related human need, we certainly would have done that as well. Unfortunately, there are no simple answers to either of these problems. Combining them only compounds the difficult search for answers.

The monograph offers thoughtful discussion about the elements of a successful strategy to prevent and control cancer in Appalachia. Not all the pieces fit together nicely. The Appalachian region is huge and diverse. Safe generalizations about the region are few and far between. What may be true of Appalachian New York will not apply to Appalachian Georgia. What may be true of one county in eastern Kentucky may not be true of another. Compounding the problem of the vast area of the region and its diversity is the scant information we have about health status in the region, including specific information on cancer. Problemsolving interventions by community-based coalitions offer one common element for each discussion. Even here, however, the discussions begin with different assumptions and information. Some authors consider the ALIC program a bottom-up approach; others see it as a top-down approach. This view depends on differing assumptions about community, class, and professional roles. Some contributors discuss the contexts of coalition efforts (e.g., regional and national programs) and problems. Others discuss coalition building from the perspective of health care providers, cooperative extension services, established community organizations, and others through less formal community leadership, including the protests of health care and other activists.

You may not find the complete answers to important questions here, but you will find a description of different paths that people suggest we take to deal with one element of the American health care crisis. We present a range of opinions within one set of alternatives related to community-based coalition efforts to control and prevent cancer. Our purpose is to inform you of what others will do and to invite you to participate in making their efforts better and more effective.

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SECTION I

The Lay of the Land

SECTION 1

The Lay of the Land

Where is Appalachia? What is Appalachia? The first question is straightforward, but its answer will surprise most readers. Media reports on Appalachia generally focus on one part of Appalachia, as Chapter 1 explains. The official definition of Appalachia, which is used by the Appalachian Regional Commission (Appalachian Regional Commission 1992), encompasses 399 counties in 13 states from New York in the North to South Carolina, Georgia, Alabama, and Mississippi in the South. Media attention generally focuses on the portion of this region that is now designated Central Appalachia. What is Appalachia? This is a far more difficult question to answer.

The chapters of this section spend much effort to explain that Appalachia is not what most people think. Obviously, these chapters do more than say what the region is not. Chapter 1 offers the geographic boundaries used in the study and discussion of Appalachia. It emphasizes that *what we think* about Appalachia has a lot to do with *how we know* about the region. Appalachia serves as a national frame of reference about a set of conflicting American experiences: poverty and abundant natural resources, desperate human need and exemplary self-reliance. Chapter 2 further explains the diversity within the region by exploring the economy of the region. Different industries—coal, steel, textiles, timber, and so forth—have concentrated in different parts of the region with very different results for the wealth of the region and areas within it. Appalachia was central to the industrialization of the United States, and Chapter 2 explains the region's current economy as a reflection of the American postindustrial economy. The economic conditions and challenges of the Appalachian area, as Chapter 2 explains, are part of national economic change and the challenge to the American social welfare system.

Chapters 3 and 4 address health conditions in the Appalachian region. Chapter 3 offers a broad concept of health that incorporates elements of community. It dispels myths and misconceptions of health in Appalachia and then offers measures of health status in the region. The maps and tables of Chapter 3 are original to this volume and represent new data for community-based health coalitions. Chapter 4 explains the resources with which health coalitions have to work. This chapter places Appalachia in the context of rural health needs and resources and explains health programs that restrict or provide access to health providers. Like the data in Chapter 3, the analysis in Chapter 4 is original and provides new information on existing health care resources in the Appalachian region. These two chapters offer community-based

coalitions a point of comparison between their own efforts and existing health care resources in Appalachia.

The success of community-based coalition efforts, such as the Appalachia Leadership Initiative on Cancer (ALIC), depends on organized effort in addition to resources. Chapter 5 provides an overview of community-led organized efforts for change in the Appalachian region since 1960. In addition, the chapter distills lessons from these efforts that are applicable to the community-based effort that ALIC projects represent.

Taken together, the chapters in this section offer the "lay of the land" for community-based coalition efforts to improve health care, specifically cancer prevention and control. They offer generalizations about the Appalachian region and cautions about what we think we "know" about it. They offer new measures of economic need, illness, and health care resources as well as reflections about the organized efforts of people in the region to improve them. They offer the Appalachian context for those who would undertake to improve health status and health care in the region.

Any such effort would join a rich and distinguished tradition of health care innovation in Appalachia. For most of the 20th century, the combination of human need and economic change has stimulated a search for new and effective means to meet the health care needs of people in the region. The Frontier Nursing Service introduced nurse midwifery to eastern Kentucky long before the rest of America was ready to accept it. The coal company towns of Kentucky, Pennsylvania, Virginia, and West Virginia established prepaid health care throughout Appalachia. After World War II, "fee for service" was advocated as a "reform" for health care in the company towns. Community clinics, started in the 1960s, pioneered the use of physician assistants and nurse practitioners to provide rural health care. Reimbursement for their services started within the region and extended to federal programs through the Rural Health Clinics Act of 1978. The region has regularly established practices that are now widely accepted as innovations or possible reforms for the problems of American health care.

Appalachia's reforms remained in the forefront after World War II as well. The United Mine Workers of America introduced the most generous health benefit program any industrial union has ever undertaken. Other unions in the region imitated the coal miners with extensive insurance coverage. The coal miners went further and established health resources, including the first comprehensive community health services clinics. These became prototypes of the community health centers that sprang up in Appalachia and across the country after 1965 when federal funding became available to support programs to develop these centers (Couto 1983). As Chapter 4 indicates, the region has many of these centers operating today. Likewise, the region currently is making efforts to improve maternal and infant health through the use of trained outreach workers recruited from among community residents (Clinton 1992).

ALIC projects continue a tradition of health care innovation in the Appalachian region. They will incorporate the principles of health promotion efforts by community-based coalitions, disseminate and refine those principles, and, undoubtedly, innovate other principles. Like any continuation of tradition, the ALIC projects will build on the remnants of reforms and innovations that preceded them and will collaborate with the continuing expression of other reforms in the region and the nation. The chapters of this section offer solid ground to understand current needs and resources and to undertake innovation within a tradition of reform and change.

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CHAPTER 1

Appalachia

Richard A. Couto

The Appalachian region has had many different boundaries. Currently, the Appalachian Regional Commission (ARC) uses a specific geopolitical definition of 399 counties in 13 states. Previously, social scientists used several different sets of boundaries to delineate the region. In addition to geographic boundaries, Appalachia denotes a distinct cultural region of contradictory and incorrect popular conceptions focusing on quilts, dulcimers, and images of universal poverty and hardship. All these elements of the popular conception of the region can be found in Appalachia; none of them describes the entire region or all the people who live there. These cultural images offer conflicting interpretations of the region but only a small sense of the diversity to be found there. It is difficult to make a safe generalization about the Appalachian region. This chapter offers an overview of the region that explains why generalizations are difficult. It examines geographic and cultural boundaries of Appalachia and offers an analytical framework to understand cultural representations of the region.

Defining the Geographic Regions

Different researchers have used various geographic boundaries for the region. Early sociologists, like Campbell (1921) and Kephart (1913), established boundaries, such as the southern highlands, that united a group of people with some common cultural characteristics. Kephart's study incorporated an uncertain number of counties in the Great Smoky Mountains region of North Carolina, Georgia, and Tennessee. Campbell's study offered a much broader definition—210 counties in 9 states extending north of Kephart's region. A 1960 study by the Maryland Department of Economic Development expanded the boundaries of the region to 11 states from New York to Alabama (Ford 1962). A survey conducted by Ford (1962) included 205 counties in just 6 states. By the mid-1960s, a half-century of analysis had provided several different geographic boundaries for Appalachia.

In 1965, the Appalachian Regional Development Act, which created the Appalachian Regional Commission (ARC), drew the boundaries of the region once again. These boundaries, the most expansive to date, have become widely accepted. They follow the spine of the Appalachian Mountains from the southern tier of New York counties to a tier of northeast Mississippi counties. The region in 1993 encompassed 399 counties and 13 states, including all of West Virginia and portions of Alabama, Georgia, Kentucky, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, and Virginia.

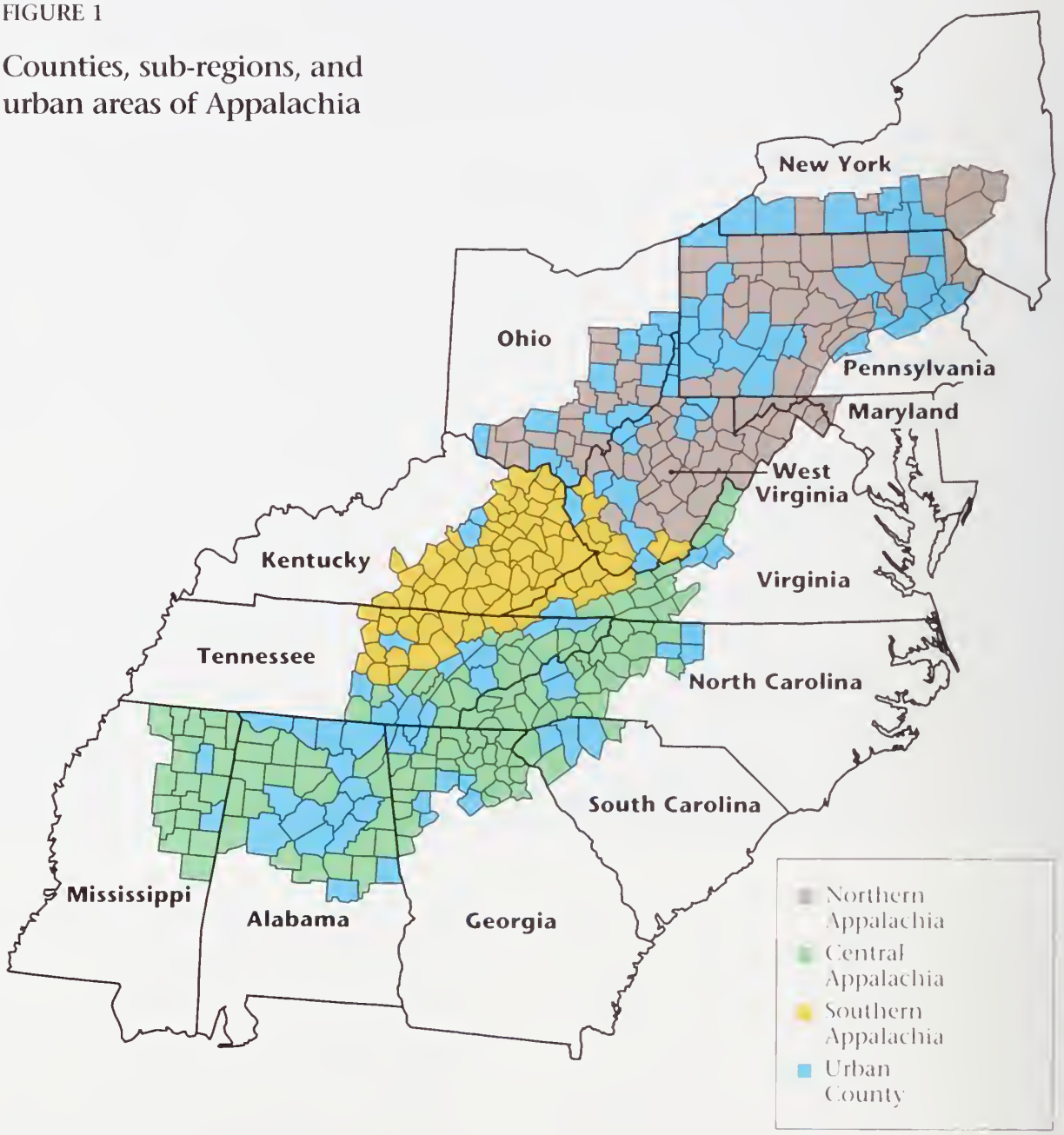
The current definition, like that of ARC, came from a national sense of acute human need within a region and a national commitment to do something about it. It also resulted from an effort of state and congressional leaders to include their jurisdictions in an area of

special federal initiatives. Federal administrators welcomed this initiative. They built much congressional support for the Appalachian Regional Commission, a fledgling agency of the Kennedy administration, which was a precursor of "War on Poverty" programs in the 1960s. Geography interacted with centers of power in Washington, D.C., to push the region's boundaries farther and farther. Initially, the ARC region included only 11 states. New York was added because it was contiguous. Mississippi was added also because it was contiguous and contained two senior U.S. senators who could be powerful friends to a federal program (Raitz and Ulack 1984). The region continued to change at its edges. It gained one Ohio county in 1991 and a Mississippi county in 1992.

Thus, the Appalachian Mountains are only part of the logic of this broad geographic definition. Other parts of that logic include economic similarities, contiguity, measures of low income and human well-being, and congressional representation of 26 senators and 59 members of the House of Representatives. That logic continues with some changes. The region now has 60 House members, an increase of 1 despite slower population growth than the rest of the nation. Some Appalachian states lost congressional representation (e.g., New York), and others gained (e.g., Georgia). More than 25 years of programs and reports create additional reasons to accept ARC's geographic boundaries. In addition, local political and business elites in 399 counties are now organized into economic development areas and provided local support, giving the region an additional unique feature. In some ways,

FIGURE 1

Counties, sub-regions, and urban areas of Appalachia



this geographic definition continues former definitions but adds specific political and administrative criteria.

Nearly all geographic definitions of Appalachia encompass an area with diverse economies and populations that make generalizations difficult. ARC's definition compounds this difficulty. It includes areas that forged the heart of the Industrial Revolution with steel and coal. Areas of the region demonstrated the possibility of mass production of goods and textiles and pioneered in the development of chemicals and plastics. Other parts of Appalachia with economic bases of agriculture and tourism remain only indirectly touched by the Industrial Revolution. This part of the region includes numerous rural counties with populations

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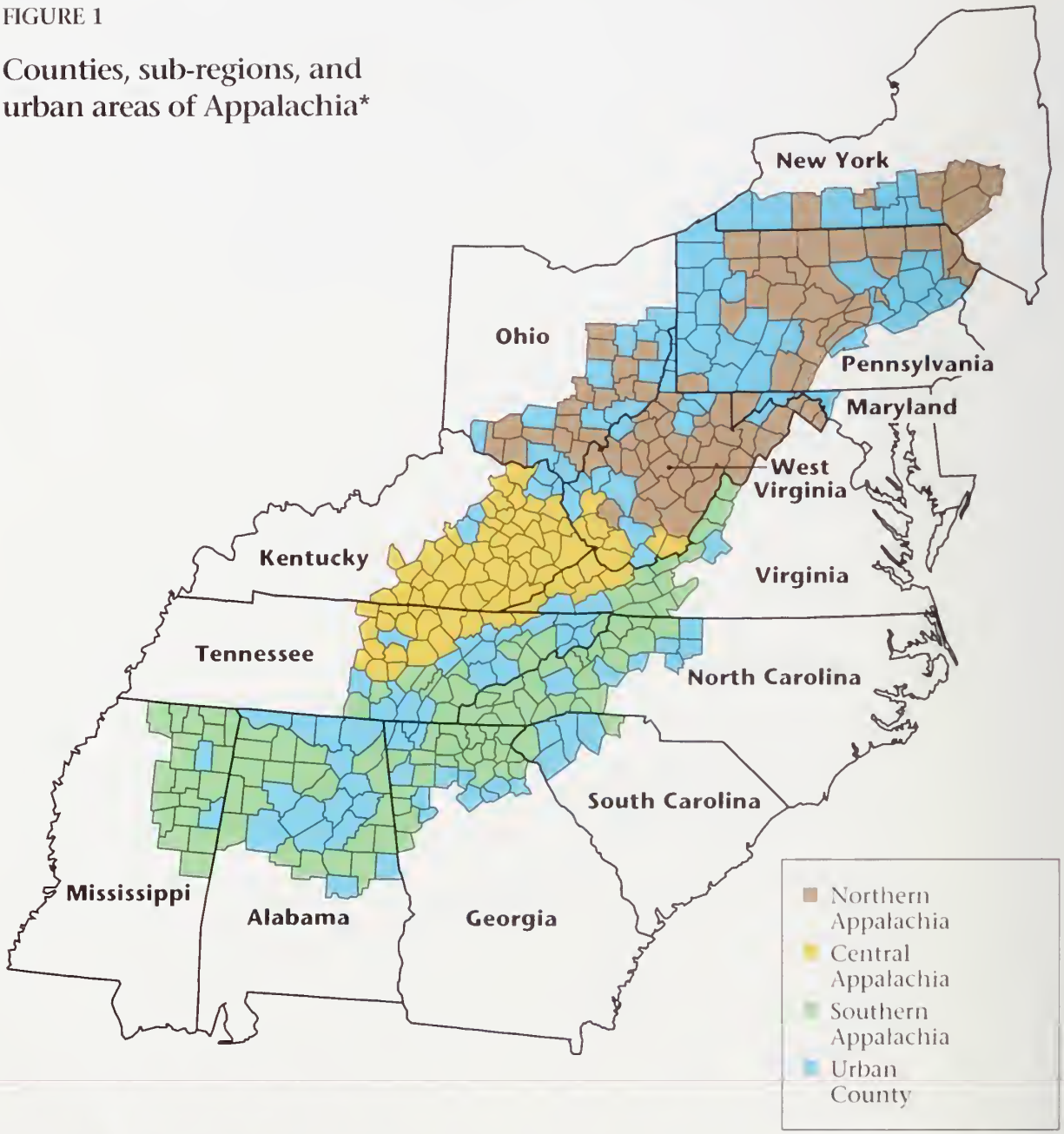

**See Appendix F for definition of urban county.*

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of less than 10,000. On the other hand, the region includes Pittsburgh and Birmingham and is contiguous to other major metropolitan areas including Atlanta, Cincinnati, Harrisburg, Lexington, Memphis, and Montgomery. Other major cities, including Albany, Baltimore, Buffalo, Cleveland, Columbus, Nashville, New York, Philadelphia, and Washington, D.C., are within an hour's drive of ARC's Appalachian boundaries.

Analysts concede the diversity within the Appalachian region by use of subregions: Northern, Central, and Southern Appalachia. The northern subregion takes in most of the older industrial area of the region and the nation, including all the Appalachian counties in Maryland, New York, Ohio, and Pennsylvania. In addition, counties in Virginia and West Virginia are included in Northern Appalachia. Central Appalachia, the smallest of the subregions, includes all the counties of eastern Kentucky and some of the Appalachian counties of Tennessee, Virginia, and West Virginia. Southern Appalachia includes the remainder of Appalachian counties of Tennessee and Virginia as well as all the Appalachian counties of Alabama, Georgia, Mississippi, North Carolina, and South Carolina. As discussed later, measures of socioeconomic well-being and the economies of these subregions vary widely. There are profound differences among counties in the same subregion as well.

Another distinction among the counties of Appalachia involves their urban or rural status. Appendix F provides an explanation of how urban and rural counties are defined in this monograph. Two hundred and sixty-six counties (67 percent) of the region are rural. Thirty-two percent of the Appalachian population resides in these rural counties, whereas only 15 percent of the total U.S. population lives in rural counties. Central Appalachia has the fewest number of urban counties. Figure 1 offers a view of the boundaries of Appalachia, delineates the urban counties of the region, and sets off the three subregions. Obviously, this geographic region is not the hidden, socioeconomically homogeneous, remote, and distinct region that may reside in the popular imagination.

Demographics

Population changes have occurred differently among the subregions of Appalachia. The entire region increased its population by a mere 1.6 percent from 1980 to 1990 compared with a national increase of 9.8 percent (Appendix A). Southern Appalachia increased its population during this period by 9.4 percent—mostly in the urban counties, which grew by 10.8 percent (Appendix B). These figures obscure the incredible growth in suburban Atlanta. There, the population growth of one county—Gwinnett County—accounts for 56 percent of all of Appalachia's increased population between 1980 and 1990 (Appendix A).

Northern Appalachian counties had a population decline (3.1 percent) from 1980 to 1990, especially among the urban counties of that subregion (3.9 percent). Central Appalachian counties lost more population (4.7 percent). Rural counties in both Northern and Central Appalachia decreased in population (0.3 percent and 5.1 percent, respectively). These losses compare with the national average gain in rural areas of 2.7 percent in the same decade (Appendix B). Table 1 compares 1980 and 1990 population figures for the Appalachian portions of each state. Appendix A provides the 1990 population of each county and the percent population change from 1980 to 1990.

Figures from the 1990 census indicate that 20.7 million or 8 percent of all Americans live in Appalachia. Fifty percent of them live in only three states—Alabama, Pennsylvania, and Tennessee. African Americans constitute 7.3 percent of the region's population but a much larger segment of the Appalachian populations of Alabama, Mississippi, and South

TABLE 1

Appalachian population by state, 1980 and 1990*

Appalachian Part	Population		Change	
	1980	1990	Total	Percent
Alabama	2,430,244	2,529,623	99,379	4.1
Georgia	1,103,971	1,508,030	404,059	36.6
Kentucky	1,077,095	1,045,357	-31,738	-2.9
Maryland	220,132	224,477	4,345	2.0
Mississippi	498,374	510,400	12,026	2.4
New York	1,083,241	1,088,470	26,874	0.5
North Carolina	1,217,732	1,306,682	88,950	7.3
Ohio	1,376,130	1,372,893	-3,237	-0.2
Pennsylvania	5,994,240	5,769,410	-224,830	-3.8
South Carolina	793,040	888,057	95,017	12.0
Tennessee	2,073,834	2,146,992	73,158	3.5
Virginia	549,888	517,816	-32,072	-5.8
West Virginia	1,950,183	1,793,477	-156,706	-8.0
Appalachia	20,368,104	20,701,684	333,580	1.6
United States	226,545,805	248,709,873	22,164,068	9.8

**Data for 399 Appalachian counties.*

Source: Appalachian Regional Commission

Carolina. Native Americans make up less than 1 percent of the population of the region and are concentrated primarily in western North Carolina. Table 2 provides a breakdown of the 1990 Appalachian population by race and state.

What We Know About Appalachia

After the boundaries have been set and the people counted, the question occurs: What is special and unique about the Appalachian region? Writers, journalists, and video and camera crews have visited specific places within Appalachia's boundaries to explain mistakenly how the characteristics of the people found there express a variation of American experience: dialect, a specific rural lifestyle and subsistence agriculture, godlessness, godliness, violent family feuds, excessive parental affection, industrial work, exploitation of labor, organized resistance of workers to exploitation, or poverty in large amounts and severe forms. Even the early, more focused studies of Appalachia conducted by Kephart (1913) and Campbell (1921) cautioned against generalizations concerning the residents of the region. Campbell explained that the people of Appalachia were socially heterogeneous, despite being white in overwhelming numbers and living in a specifically defined contiguous area. Moreover, he understood that statements about people in the remote rural areas of his

TABLE 2

1990 Appalachian population* by race and state

Appalachian Part	White†	Percent White	African-American	Percent African-American
Alabama	2,026,236	80.1	503,387	19.9
Georgia	1,413,612	93.7	94,418	6.3
Kentucky	1,029,300	98.5	16,057	1.5
Maryland	215,592	96.0	8,885	4.0
Mississippi	353,169	71.2	142,520	28.8
New York	1,068,223	98.1	20,247	1.9
North Carolina	1,187,852	90.9	118,830	9.1
Ohio	1,344,130	97.9	28,763	2.1
Pennsylvania	5,537,522	96.0	231,888	4.0
South Carolina	738,341	83.1	149,716	16.9
Tennessee	2,027,240	94.4	119,752	5.6
Virginia	504,505	97.4	13,311	2.6
West Virginia	1,737,182	96.9	56,295	3.1
Total:	19,182,904	92.7	1,504,069	7.3

* *Data for 398 Appalachian counties.*

† *White population figure includes all other race/ethnicities that total less than 1 percent.*

Source: Appalachian Regional Commission, unpublished data

study could not be applied with equal accuracy to the people in the same region who lived in towns and valleys (Campbell 1921).

As the boundaries of Appalachia expanded, the differences among people within the region also grew, making generalizations about residents in the region even more difficult. For example, how do residents in Ithaca, New York, and Tupelo, Mississippi, share an Appalachian culture; or residents of Pittsburgh and the Atlanta suburbs; or Binghamton, New York, and Estill County, Kentucky?

Generalizations about the residents of the Appalachian region and their culture come primarily from disregard of cautions about extrapolating from one set of people to another, from one place to another, or from one time to another. Very few studies encompass the entire region and its many issues. Most studies deal with Central Appalachia—eastern Kentucky and contiguous portions of east Tennessee, southwestern Virginia, and southern West Virginia. Other studies are even more limited to a particular community in a particular county in Central or Southern Appalachia.

Caudill's influential book (1962), *Night Comes to the Cumberland: A Biography of a Depressed Area*, is still a widely read classic and a very good historical introduction. However, it addresses only a portion of the coalmining counties in eastern Kentucky. There are prob-

lems extrapolating Caudill's work to other coalmining counties, as well as to the non-coal counties, of eastern Kentucky. Based on Caudill's work, it is simply impossible to generalize, for example, to the anthracite coalfields of Pennsylvania, to the portion of Central Appalachia that is not coal mining, or to the rest of the region as defined by ARC.

Caudill's book mixes two strong but distinct interpretations of the problems of the Central Appalachian region. Caudill blames the social origins and inbreeding of the region's residents for its political, social, and economic problems. In this, he resembles those who have used a culture-of-poverty analysis to explain the region. Weller's (1965) prominent work, *Yesterday's People*, illustrates this approach as do numerous other studies most often written by helping professionals, including mental health workers. Cunningham (1987) has taken up the cultural interpretation most recently in his book—*Apples on the Flood: The Southern Mountain Experience*—although much more adroitly than others and without victim blaming. Caudill's work is so rooted in victim blaming that psychologist Arthur Jensen, in a television interview with journalist William Buckley in the early 1970s, averted charges that his studies of IQ and African Americans were racist by appealing to Caudill's work.

On a more popular front, *The Foxfire Book* (Wigginton 1972) emphasized Appalachian culture in a much more positive manner. These accounts of folklore and folkways portray a self-reliant, talented, and intelligent group of rural people. However, generalizations can no more be made from this work, done primarily in rural, northern Appalachian Georgia, than they can from Caudill's work.

As a result of numerous studies and reports, Appalachia conjures up conflicting and inaccurate images of people who live there. On the one hand, we have television's "The Waltons," offered as a model in the 1992 Republican presidential campaign on family values; on the other hand, we have the Hatfields and the McCoys, commercialized as bumbling bumpkins or fiendishly cruel, like the residents of rural Georgia portrayed in the film *Deliverance*. Similarly, popular images suggest the cartoon indolence and innocence of Li'l Abner and Snuffy Smith and news coverage of the grueling work and militancy of nameless coal miners.

Scholarly examinations trace the popular concepts of Appalachia and their origins back to national trends in markets for literature and social interventions. Literary magazines seeking short stories of local color found them in descriptions of parts of Appalachia. Social workers in settlement schools found contributions for their work in responses to their descriptions of the needs of the residents of the region whom they served and the many more they did not (Shapiro 1978). Later, political and social activists looking for places that needed change found them in the conditions of poverty in Appalachia as well (Batteau 1990). People outside the Appalachian region often have defined the region in terms of their commercial, financial, social, or political needs. This is not to say there is no accuracy in the accounts that we have. It does suggest an additional reason why the generalizations we have of the Appalachian region may be misguided as well as misinformed.

In addition to his emphasis on the characteristics of the Appalachian people in his study, Caudill (1962) also interpreted the region's problems in terms of corporate control and related political collusion. Others have built on this interpretation to place Appalachian events and conditions into the mainstream of American life and processes of industrialization and economic development. In these studies, Appalachian conditions of poverty and human need are more the consequence of economic decision making by coal companies, textile mills, the timber industry, and absentee landowners. The region's extractive industry sends minerals and timber to

wealthier areas and receives as little in return as possible. Legislation to benefit the companies developing the raw materials of the region left local and state governments with little tax base to provide essential services such as education, medical care, and public health. The political corruption that went into forming this legislative inequity left reformers with few avenues to justice (Appalachian Land Ownership Task Force 1983; Eller 1982; Gaventa 1980; Lewis et al. 1978). One study reinterprets the feud of the Hatfields and the McCoys, which has stimulated so many stereotypes of "hillbillies," in terms of the economic transformation going on at the time (Waller 1988).

Unlike the cultural interpretations of Appalachia, these studies emphasize what national economic and political forces have done to the region. Likewise, rather than an interpretation of a culture that incapacitated citizens to resist negative influences, these studies suggest how people fought back against such forces. When taken together, even these studies of the Appalachian region are limited in providing an overview of the region broadly defined by the Appalachian Regional Commission. They also focus on a particular set of counties, once again most often in Central Appalachia; a particular time; or a particular industry (e.g., coal, textiles, steel).

In sum, what we "know" about Appalachia is largely extrapolated from case studies, most often from Central or Southern Appalachia; from historical studies of a set of counties, an industry (e.g., coal), or labor union efforts; and from cultural descriptions and interpretations of very specific places or practices. What we "know" often obscures the fact that Appalachian residents, regardless of subregion, are average and ordinary human beings, who under a given environment will develop like other human beings. Part of the problem of Appalachia is what we "know" about it and have to unlearn. In this regard, Appalachian social problems resemble other social problems such as race (Du Bois 1935, p. iii).

Addressing the social problems of Appalachia, no less than any other region, requires knowledge of the social and historical factors that have shaped those problems and the cultural responses that residents of a particular place have fashioned. If there is a culture of poverty, it is in large part a response to the poverty in which people found themselves living and a reasonable response to their prospects of escaping it. Likewise, if there are cultural traits like fatalism, they are likely, in large measure, to be a response to the lack of resources required to improve a condition. Much of the historical and social analysis of the region provides only for safe generalizations of particular places at particular times. As with any other region, we have to accept change over time in the same place and differences among places even in the same region. The expanse of the Appalachian region and the conflicting standards used in defining it make these cautions about generalizations essential. We have become especially cautious in making generalizations about Appalachian culture, the topic to which we now turn.

The Cultural Representation of Appalachia

Few areas of Appalachia attract more attention today than the area of culture. Caudill's (1962) and Weller's (1965) emphases on unique characteristics such as fatalism remain popular, especially among helping professionals who are new to the region and seek to adapt to the culture. Caudill and Weller offer handy hooks on which it is easy to hang innovative interventions and expressions of concern. Their interpretations allow helping professionals to portray the region as beyond the mainstream waiting to be brought in with the tools of professional intervention. Burkett and Fisher discuss examples of these close encounters of the cultural kind in Chapters 3 and 5, respectively. Cultural factors related to

health intervention manifest themselves, at least indirectly, in all the other chapters in this monograph.

Work following that of Caudill and Weller explains Appalachian culture in positive terms and the seemingly differentiating negative characteristics as expressions of differentiating economic circumstances. Prominent among these later cultural treatments, Appalshop, a media collective in Whitesburg, Kentucky, tells the virtues of Central Appalachia in film, video, radio broadcast, and theater. Individual Appalachians contributed the major portion of this recent work on the positive cultural traits of Appalachians. Often their studies begin with a narrative account in which they acquire their Appalachian identity only upon contact with institutions, such as colleges, away from their home; this acquisition imparts shame for their origins and their low circumstances; they reclaim their pride in the virtues of their unique, no longer suppressed identity; and they present their current work as one variant of the valuable multicultural American experience (Blair 1993).

In some cases, these authors defiantly assert the superiority of Appalachian ways over others. For example, Grigsby (1993) contrasted his working-class background of the coalmining region of eastern Kentucky with the middle-class, academic culture of which he is now a part as a college teacher. In particular, he recalled his chagrin at the conduct of his departmental chair who expressed anger that Grigsby had not attended a party and had not responded with his intention to come or not to come. That anger was coupled with disbelief and disdain that Grigsby did not know what RSVP means. Grigsby then counterattacked in this conflict of cultures.

> *I don't like "RSVP" invitations. I don't like being forced to decide early to attend an event and then be forced to go later if I don't want to, and I'm convinced that the working-class approach to such functions ("Come if you want and can and bring something to eat or drink") is a more logical way to conduct "parties," or to use the working-class word—"get-togethers"—which is again more logical (Grigsby 1993, p. 8).*

This form of cultural counterattack comes with deep resentment—"dismay and venom" (Speer 1993, p. 12)—over the continued assumption of inferiority of Appalachian culture. Tracing their intellectual protest back to work of Branscome, Seltzer, Whisnant, and others in the early 1970s, these recent accounts testify to the staying power of pejorative stereotypes of "hillbillies." Other ethnic groups have exemptions from comic books; for example, one does not find comic books on Hasidic Jews, Mormons, or Latinos. Likewise, it is hard to imagine finding a book on how to speak "eastern" as easily as one finds books on speaking "southern" and "hillbilly." We continue to caricature Appalachia, however, in whole and in part, in comic strips, television shows and reruns, movies, and even in countless souvenir shops at interstate exits throughout the region.

It is simply inconceivable that after the civil rights movement we would base our understanding of African Americans on blackface comedy, such as television reruns of "Amos and Andy." Social and political change has come with cultural changes regarding race. This has spilled over into other areas such as gender. Thus a "Women's Joke Book" would be funny to more people if it contained jokes told by women instead of jokes told by men about women. These changes contrast sharply with the unchanged status of Appalachian cultural stereotypes (Crawford 1993). In the mid-1980s, John Shelton Reed affirmed the continuation of what others had pointed out in the early 1970s: "Hillbillies appear to be the last acceptable ethnic fools" (Speer 1993, p. 18).

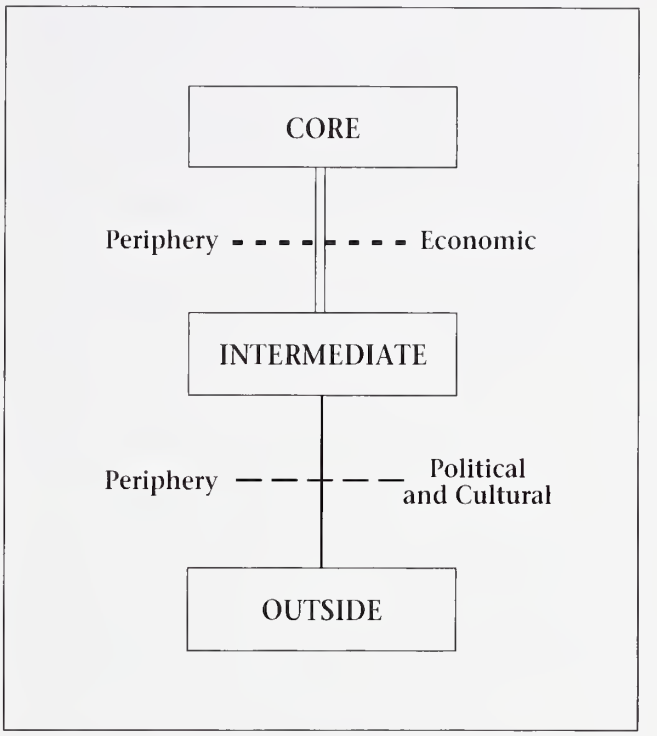
These observations illustrate a much larger background of cultural representation that has been addressed by other writers. For example, Batteau assumes that stereotypes

are images made in the context of intergroup relationships in which "different groups seek to impose their will on others" (Batteau 1990, p. 199). Similarly, Whisnant (1983, p. 6) relates Appalachian cultural representation to the politics of culture. In the latter, misleading concepts of local people are disseminated to people with influence and wealth as part of the interaction of very different cultural systems. The distant cultural systems (e.g., centers of industrial capital in the United States in the late 19th century) focus on parts of the local culture. By separating parts of local culture from the broader social, political, and economic history that explains local culture, the distant cultural systems obscure the political implications of their own efforts to change local culture (Whisnant 1983, p. 16). In doing so, these distant cultural systems assume the superiority of their own cultural forms and establish the justification for their efforts at change.

Cunningham (1987) places Whisnant's work in an intermediary range of cultural conflict. Cunningham views culture, politics, and economics as a seamless web woven from the interactions of three groups: the metropolitan core region or civilized group, the outside region or savage group, and the intermediate region that lies between the two other groups. He applies his analytical framework to the interaction of Rome (civilized, metropolitan core), the Celts and Scottish highlanders (the savage outside region), and the Scottish lowlanders and Ulster Irish (the intermediate region). Cunningham applies this same analysis to the Appalachian region as well: the American east coast, Appalachia, and Native Americans. His analysis has the limits of any effort that attempts to connect events and conditions 19 centuries apart and of most efforts to explain Appalachia by focusing on one part of it.

Cunningham's analysis, on the other hand, provides a framework to analyze cultural representations of Appalachia. Figure 2 represents

FIGURE 2. Portrayal of Cunningham's regions and boundries



that framework. Between the core and intermediate regions is an economic boundary that the core region penetrates sufficiently to develop economic relations. Between the intermediate and outside regions lies a more rigid political and cultural boundary, like Hadrian's wall demarcating Roman boundaries on the British Isles. The first boundary is permeable. Culture flows from the core region to the intermediate region primarily, and economic goods flow from the intermediate region to the core region primarily. The second boundary is far less permeable and represents the border where, the core group believes, commercial and cultural exchanges are not useful and perhaps dangerous. People venture from the intermediate region and the core region to the outside region primarily to verify the savage nature of the region, the need for rigid boundaries, and the superiority of the other two regions. Virtue is bestowed on those in the outside region who pass the boundaries into one of the other two regions.

Cunningham's borders and regions apply

to much of what we already have discussed about Appalachian cultural representation. If we keep in mind the economic borders as well as the political and cultural borders disputed by the core and outside regions, we can understand the feud between the Hatfields and the McCoys as a conflict over the permeability of the economic border and the reinforcement of the rigid cultural and political border. Waller's (1988) interpretation of the feud certainly supports this. Cunningham also helps us understand the work of Caudill and Weller. On the one hand, they provide a permeable boundary for the expression of concern of the core region for the intermediate region. On the other hand, Caudill and Weller provide an intermediate region by portraying an outside region where "savages"—insufficiently civilized human beings—have been replaced with "dolts"—insufficiently intelligent or motivated human beings.

Similarly, Cunningham helps explain the shame so many Appalachian professionals feel when they come into contact with the metropolitan core. They are mistaken for "savages" from the outside region. They work hard to pass through the cultural border to the intermediate region as well as through the border to the core. Cunningham ascribes an impaired identity to such people, of which he is one: "a peripheralized people...victims of (among other things) distorted rites of passage which reinforce these insecure ego-boundaries and ego-foundations" (Cunningham 1987, p. xxiii).

However useful, Cunningham's analysis has its limits as well. The boundaries, for example, are defined from the core region out. Although this is accurate in terms of power relations, an essential part of culture, it assumes the cultural superiority established by those power relations. Similarly, those boundaries and the individual and collective identities that culture imparts are not static. Even Hadrian's wall was tested, breached, and reinforced.

Like some members of any group, some Appalachians protest their pejorative portrayal: the boundaries of culture that others establish. They may do so vociferously as the coal operator did in the film *Rich Land, Poor People.* He complained on camera to the camera crew about media portrayals that focused on poverty exclusively. Other Appalachians may protest modestly as one Appalshop character explains in *Strangers and Kin*, a film about negative stereotypes in Appalachia. He recalled being called to the school auditorium to select a pair of shoes from the hundreds of pairs sent in reaction to a televised documentary on poverty in eastern Kentucky. His father's face expressed disappointment in himself, as provider, and in his son, for accepting someone else's assessment of his need. He never wore those shoes. More recently, local Appalachian residents have used cultural protest in their efforts to block waste dumps or water projects in their communities. They interpreted these projects' premises as assumptions that the people and communities to be affected by the dumps and projects were worth little and better off moved to another location (Cable 1993; Foster 1993).

In addition to challenging the cultural borders established by others, Appalachians also use them and thus reinforce them. Town residents may deny the truth of stereotypes when applied to them, but they may assert their validity when applied to residents outside of town. Likewise, the professional class of the region may accept and extend pejorative portrayals of working-class and low-income residents, as a portion of Caudill's work did. Thus, Cunningham's distinction of a core and outside culture has a counterpart within the intermediate cultural region among people who assert their identity with core values by distinguishing themselves from those whom core values brand "hillbilly" with debilitating human characteristics. Thus, interregional cultural differences have a counterpart in intraregional cultural differences. As Campbell (1993,

p. 1) has concluded, "Some Appalachians... exhibit modernity by accepting the prevailing stereotypes as valid but only for a certain segment of the population—a segment to which they do not belong."

Despite the negative characteristics embedded in Appalachian stereotypes, some Appalachians embrace them occasionally. For example, the Appalshop film "Strangers and Kin" shows us "Hillbilly Days" in Pikeville, Kentucky, in which men and women dress up as the media caricatures them and their forebears. Similarly, Hazard, Kentucky, welcomed with open arms, or at least with a downtown parade, the characters of the prime-time television show "The Dukes of Hazzard." If anything could dispel the premise of simple generalizations of Appalachian cultural representations, it would certainly be this event. A coal town of eastern Kentucky, which came within one "z" of the fictional county, feted the cast of a television series filmed in California, set in northern Alabama, but without any African Americans. Hazard, Kentucky, proudly identified with the bungling corruption and tantrums of the political officials and with the bumpkin common sense and decency of the protagonists of the series. Such events portray the human capacity to deflect the shame embedded in stereotypes. Members of a stereotyped group often take the humor aimed at them and laugh at or with those who make the jokes.

More important, such events invite the question, which Batteau (1990) recently examined: "Whose Appalachia is this?" Obviously, as Cunningham and Whisnant make clear, Appalachian cultural representation is a field in which two different cultures conflict. Batteau, Cunningham, and Whisnant make clear that those within the intermediate region learn how to market their culture and that of the outside region. The economic boundary of the core and intermediate regions is permeable to the flow of cultural exchange in both directions when related to economics. Local officials of Columbiana County, Ohio, demonstrated that recently. Originally, they declined to be included among Appalachian counties but reversed themselves in 1991. The switch from concern with stigma to an assertion of "hillbilly" identity came in part with the lost opportunity for federal funds available through participating in programs of the Appalachian Regional Commission. At least one person embraced kinship with West Virginia, a "hillbilly" personality, as well as a "river rat" identity upon the county's entrance into the Appalachian region (Tribe 1993, p. 26).

In answer to his own question, Batteau asserts that Appalachia is a social invention like the cowboy or the Indian. It is one part positive virtues such as self-sufficiency, pioneering spirit, patriotism, independence, and the dignity of making one's humble way despite adversity. It is one part negative images of dependency, failure, retarded economic and human development, and the dismay of humble people having lost their way because of adversity. Appalachian cultural representation is also one part new and one part old. The old part is virulent racism of the 1890s. Appalachia seemed a pool of Anglo-Saxon genes to develop and thus to prove this group's superiority to African Americans and immigrants. The new part is whatever representation seems appropriate to market in a proposal for funding from federal or foundation sources. The region is also both profane and sacred—profane for the human need and environmental destruction in the region and sacred because people and land have been sacrificed for the greed of some and for the well-being of the nation.

In this regard, Galbraith, in his pathbreaking book, *The Affluent Society* (1958), and in his later reflection on American life, *The Culture of Contentment* (1992), uses Appalachia as a test of America. His latter book offers a cultural interpretation of America to explain the poverty of the Appalachian region.

America's "culture of contentment" entails a majority who are fortunate and favored or who hope to be so, who act on behalf of their own immediate short-term benefit, and who willingly tolerate the need for increased and improved social welfare policies, apparent in places like Appalachia, without doing anything to meet those needs or to achieve those policies (Galbraith 1992). Galbraith illustrates Batteau's conclusion about Appalachian cultural representations: "'Appalachia' is a frame of reference, not a fact." It is a willful association "with a broad array of other texts" (Batteau 1990, p. 200).

Conslusion

The practical implications of the cultural representation of Appalachia are made evident throughout the chapters of Section I of this monograph. After all, projects of the Appalachia Leadership Initiative on Cancer (ALIC) emanate from the core region, Washington, D.C., and the National Cancer Institute. They can entail cultural conflict—for example, efforts to change unhealthy behaviors. In addition, the effect of cultural stereotypes on residents of the same Appalachian community will affect their capacity to work together and the membership of coalition efforts. After people learn the painful experience of culture's role in exploitation, they have the opportunity to learn from it and to do better. Two primary strategies deal with negative cultural stereotypes: to protest those that others use and to do better ourselves (Speer 1993).

Behind these practical difficulties are the profoundly complex factors that create, maintain, and adapt a wide assortment of Appalachian cultural representations. Obviously, any community-based, problem-solving intervention needs to start with the history and culture of the community in which it is occurring. In Appalachia, as in every other region, this means inquiring about and uncovering those specifics. Communities in Appalachian New York vary widely from those in Appalachian Mississippi. Similarly, adjoining counties may vary as well and require different approaches in community-based problemsolving because of different histories and cultural adaptations.

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CHAPTER 1
Action Steps

1. Continue to research and study the history and culture of your local area. Identify the streams of local inmigration and outmigration, their causes, and the characteristics of the groups involved.

2. Consult local historians and conduct oral histories to learn about previous organized efforts for change (e.g., labor unions, volunteer fire departments and rescue squads) or the establishment of preceding programs of education, environmental quality, economic development, housing, or health care.

3. Help raise awareness of your area's diversity so that local coalitions can represent and respond to the needs of the different groups.

4. Begin all community intervention projects with a community needs assessment that involves all community residents.

5. Tap into local cultural and community networks throughout your area.

6. Use these networks to ensure that the varied cancer-related issues are considered for coalition activities and outreach efforts.

7. Use local coalitions to correct negative and misinformed generalizations about local people.

8. Develop an understanding of the ways in which the cultures of various Appalachian areas guide the construction of class consciousness, ethnic and gender relationships, regional identity, and community life and how these affect health status.

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CHAPTER 2

Political Economy of Appalachia

Richard A. Couto

Few elements differentiate and unite the areas within the Appalachian region as clearly as the economy. This chapter provides an overview of recent economic development in the Appalachian region. It explains that declining industries are concentrated in different parts of the region. It focuses on the social consequences of recent developments in Appalachia's dominant industries. Interpreting social conditions in the context of the economy raises issues of public policy about income, employment, and poverty. These issues are at the intersection of American politics and economics. The conditions we find in the Appalachian region are one small part of the American political economy. The multiple challenges to social welfare in the region are part of the common challenge that faces the nation.

National and Regional Economic Changes

Changes of and within the industrial sector and changes in the pattern of investments have radically restructured the American economy, including that of Appalachia, over the past 20 years. Bluestone and Harrison (1982, 1988) describe this development as part of the increased internationalization of the economy and ease of capital transactions. Other analysts emphasize the current changes in the American economy as a normal development (Fisher 1990; Reich 1991). However normal this development may be, profound changes in the lives of working people flow from decisions about the investment of capital. These changes include the amount and nature of work and its compensation.

The shift in capital and economic activity is global and obviously includes the Appalachian region (Fisher 1990). However much we might regard sections of Appalachia as geographically remote or culturally unique, the image and the goods of the region are marketed and integrated on a global scale. In simple terms, this means that one can buy "Appalachian Trail" boots, which are made in Romania, at K-Mart. In more complex terms, the integration of the Appalachian region into the global economy means that the natural and economic resources of the region are integrated into the dealings of the major participants of the global economy. Pittsburgh banks invest in steel-exporting countries, such as Brazil and Japan, whose industries compete with the declining American steel industry concentrated around Pittsburgh. Multinational corporations develop the coal reserves of Colombia and China while they close mines or demand reduced labor costs at their American coalmining subsidiaries. Extranational industries have invested in the Appalachian region as part of this global economy. The Appalachian counties of South Carolina that have shown high rates of growth in per capita income and population also have the highest rate of industrial investment, per capita, of extranational corporations of any American region. There are

obvious benefits of increased employment and income in some regions where such investment occurs.

On the other hand, capital shifts often lead to decreased employment and income in regions of former economic activity—for example, manufacturing. In Northern Appalachia, specifically, there has been a loss of employment and income in the manufacturing sector of the economy. Even here, however, the global economy plays itself out in startling ironies. Sony Corporation, for example, is opening a new plant in the recently hard-hit area of New Stanton, Pennsylvania, in a former Volkswagen plant. On the one hand, this succession of economic activity of extranational corporations is welcome news. On the other hand, it marks a net decline in manufacturing employment from 2,500 to 1,000 jobs, a shift from skilled to less skilled work, and a decrease in pay and benefits even for the workers lucky enough to find employment.

Because the Appalachian region is so diverse and because of its concentration of industries, it is a microcosm of American and global economic change. In the region, as in the nation in general, there is a shift within the manufacturing sector of the economy toward assembling of components made elsewhere, from established manufacturing locations to new ones, from labor-intensive production modes to capital-intense modes, from an organized labor force to an unorganized labor force, and from manufacturing sectors to nonmanufacturing sectors of the economy, especially services. The industries concentrated in the Appalachian region include work forces that have been in the forefront of industrial relations (coal mining and steel); work forces that have increased their organized strength in a declining industry (textiles, apparel, and furniture); and work forces that have not been organized (lumber and farming).

In the Appalachian region, the past decade has observed declines in established industrial centers of the American economy and development of new centers of economic activity. For example, urban counties in Northern Appalachia have become known as the "rust belt," reflecting the deindustrialization of the American economy. On the other hand,

TABLE 1

Per capita personal income as a percentage of the national average for Appalachia and its regions, 1969, 1979, 1989

Region	Percent of National Per Capita Income		
	1969	1979	1989
Appalachia	79.5	82.8	80.9
Northern	86.6	88.4	83.6
Central	57.7	69.0	63.0
Southern	74.7	79.1	81.9
Metropolitan Counties	88.5	91.8	90.1
Northern	93.3	96.3	91.0
Central	76.1	87.0	79.0
Southern	81.7	86.2	89.6
Nonmetropolitan Counties	70.7	74.5	72.3
Northern	78.5	79.7	75.8
Central	55.0	66.5	60.8
Southern	67.3	71.5	73.3

Source: U.S. Department of Commerce, Bureau of Economic Analysis. *Local Area Personal Income*. 1971, 1981, and 1991.

some urban counties in Southern Appalachia have become known as the "sun belt," illustrating shifts of capital and location of corporate activity. The rural counties of the entire region represent the continued languor of America's rural areas. The region has seen the growing disparity between urban and rural areas. The Central Appalachian region, in particular, is a rural area that remains between the "rust belt" and the "sun belt" as a chronically depressed belt.

Appalachian Employment and Income

These broad global and national economic changes have created practical and personal consequences in Appalachia. In particular, they have affected the income of people in Appalachian counties. Income figures from 1969, 1979, and 1989 indicate the income changes over two decades (U.S. Department of Commerce 1971, 1981, 1991).

Insofar as the risk for cancer increases with low income and low literacy, this analysis of income provides information that can be used to target higher risk counties. However, it does not identify high-risk populations within counties. This is the work of the community-based coalitions of the Appalachia Leadership Initiative on Cancer (ALIC).

Analysis of the per capita total personal incomes in the region suggests that the gap between the region and the rest of the nation has widened from 1979 to 1989 (Table 1). These 10 years combined a decade of economic decline for Northern and Central

TABLE 2

Per capita personal income as a percentage of the national average for Appalachia's 10 wealthiest counties, 1989

County	Appalachian Subregion	Largest City Within 20 Miles Miles	Percent of National Per Capita Income 1989	Percentage Point Change in Relative Income 1969-1989	Percent Population Change 1969-1989†
Forsyth (NC)*	Southern	Winston-Salem	111.7	12.3	18.9
Allegheny (PA)*	Northern	Pittsburgh	109.4	2.3	-11.5
Montour (PA)	Northern	Williamsport	104.9	22.2	-3.0
Gwinnet (GA)*	Southern	Atlanta	106.3	17.4	208.4
Broome (NY)*	Northern	Binghampton	101.9	0.8	-5.5
Polk (NC)	Southern	Spartanburg (SC)	100.6	14.5	16.7
Forsyth (GA)*	Southern	Atlanta	100.1	17.4	104.9
Madison (AL)*	Southern	Huntsville	99.9	8.7	30.4
Pike (PA)	Northern	Scranton	96.1	0.3	102.1
Whitfield (GA)	Southern	Chattanooga (TN)	95.9	8.8	17.0

**Indicates metropolitan county*

†The population change for the United States from 1969 to 1989 was 22.1 percent.

Source: U.S. Department of Commerce, Bureau of Economic Analysis 1971, 1981, and 1991.

Appalachia with cutbacks in government programs. In contrast, Appalachian income gained ground on the nation from 1969 to 1979. From 1969 to 1989, the per capita income of Appalachia increased slightly from 79.5 to 80.9 percent of the national per capita income. This increase came primarily from the gains of 3.3 percentage points in the region in the 1970s that outdistanced the loss of 1.9 percentage points in the 1980s. The regional figures of increases and declines reveal significant differences among the subregions. For example, Central Appalachia had the widest swings but still remains the poorest subregion. Counties in Central Appalachia increased their per capita income by 11.3 percentage points from 1969 to 1979. However, that same set of counties saw the largest decrease (6.0 percentage points) in the following 10 years.

Northern Appalachia gained and then lost ground. This region reported a decrease of 3 percentage points in relative total per capita personal income figures from 1969 to 1989. This overall decrease includes a decline in the 1980s of 4.8 percentage points. Northern Appalachian metropolitan counties declined in their proportion of U.S. per capita income by 5.3 percentage points in the 1980s. In 1969, the per capita personal income of metropolitan counties of Northern Appalachia was much closer to the national average than that of the metropolitan counties of Southern Appalachia (93.3 percent and 81.7 percent, respectively). In 1989, these sets of counties stood about even (91 percent and 89.6 percent, respectively).

TABLE 3

Per capita personal income as a percentage of the national average for Appalachia's 10 poorest counties, 1989

County	Appalachian Subregion	Percent of National Income 1989	Percentage Point Change in Relative Income		Population Change 1980-1990*
			1969-1979	1979-1989	
McCreary (KY)	Central	38.9	9.9	-2.4	-0.2
Menifee (KY)	Central	40.4	0.8	-4.5	-0.5
Elliott (KY)	Central	40.8	13.7	-8.4	-6.6
Owsley (KY)	Central	41.7	6.0	2.9	-11.8
Clay (WV)	Central	42.2	10.5	-12.9	-11.4
Jackson (KY)	Central	42.5	4.0	-2.2	-0.3
Magoffin (KY)	Central	44.2	17.4	-7.8	-3.2
Summers (WV)	Central	44.3	3.0	-10.3	-10.5
Clay (KY)	Central	44.7	19.6	-9.3	-4.4
Kemper (MS)	Southern	45.0	14.1	-8.8	2.0

**The population change for the United States from 1979 to 1989 was 9.6 percent.*

Source: U.S. Department of Commerce, Bureau of Economic Analysis 1971, 1981, 1991; Appalachian Regional Commission 1991.

Whatever the plight of metropolitan counties, nonmetropolitan counties still lag behind them in Appalachia and in each subregion. Since 1969, the regional gap between metropolitan and nonmetropolitan counties apparently has remained the same at about 18 percentage points. Metropolitan and nonmetropolitan counties stood at 88.5 percent and 70.7 percent, respectively, of the national per capita income in 1969. In 1989, these figures increased somewhat for each set of counties to 90.1 percent and 72.3 percent, respectively.

The brightest news in the region is in the Southern Appalachian counties. Per capita total personal income increased from 1969 to 1989 and in each decade of that period. Gains were greater in the metropolitan counties of Southern Appalachia, especially around Atlanta and Winston-Salem. This increase widened the gap between them and the nonmetropolitan counties in Southern Appalachia. The nonmetropolitan counties showed improvement as well, but not as much improvement as the metropolitan counties.

By 1989, only eight Appalachian counties had per capita incomes at or above the national level. Five of them were in the southern region. An examination of the 10 counties with the highest per capita income reveals the complex patterns at work in the region. Table 2 lists the counties, the largest city within 20 miles, the percent of national per capita income, change in percent of national per capita income from 1969 to 1989, and the rate of population increase during those two decades.

Some elements of a pattern among these 10 counties are apparent and significant. The two metropolitan counties in Northern

Appalachia (Allegheny, Pennsylvania, and Broome, New York) experienced very modest gains in per capita income and significant population decline. The four metropolitan counties in Southern Appalachia (Forsyth, North Carolina; Gwinnet, Georgia; Forsyth, Georgia; and Madison, Alabama) witnessed large gains in per capita income ratio and large population increases. The increases of both measures suggest economic growth that attracts newcomers. On the other hand, it may indicate a population shift of the economically more advantaged from nearby urban areas. For example, the two counties surrounding Atlanta (Gwinnet and Forsyth) may reflect both the growth in the size and wealth of Atlanta and a movement from the city to outlying areas. Such shifts are part of the pattern of the increased political and economic power of suburban areas. Madison County, Alabama, reflects the benefit of increased military spending in the 1980s. Montour County, Pennsylvania, is a case of a Northern Appalachian nonmetropolitan county that increased per capita income significantly through increased earnings in the service sector but still lost population. The Geisinger Medical Center provides more than 3,200 jobs in Montour County. This snapshot of the "wealth" of Appalachia suggests the complexity of the region. There are different rates of economic growth among the more affluent counties and population increases and decreases among them as well.

A different pattern appears among the 10 poorest Appalachian counties (Table 3). All but one of them are in the central region. All have per capita personal incomes at or below 45 percent of the national average. All of them gained ground in absolute and relative terms in per capita income in the 1970s. Most lost significant ground in the 1980s. With the exception of Kemper County in Mississippi, there has been a decline in population among these counties during the 1980s.

Regional Differences within Appalachia

The different regions of Appalachia gained and lost in their per capita income in strikingly different ways. The Central Appalachian region gained most from 1969 to 1979, thanks in part to the energy crisis and the demand for coal at increased prices, and lost most from 1979 to 1989. The Northern Appalachian region, with the decline of the steel industry and changes in the manufacturing sector of its economy, gained least from 1969 to 1979 and lost a great deal in the 1980s. Over this two-decade period, this region lost in overall per capita personal income relative to the national average. The Southern Appalachian region, on the other hand, showed the greatest gain from 1969 to 1989, caused primarily by the development of urban areas like Atlanta, Winston-Salem, and the northwest corner of South Carolina. Table 1 indicates the relative gains and losses of each region from 1969 to 1989.

Bright Spots and Shadows in the "Sun Belt"

Much of the current economic growth and improvement within the Appalachian region is concentrated among the Southern Appalachian counties, especially within Appalachian Georgia. Nine of the 10 counties that have the largest increase in their per capita income from 1979 to 1989 are in the South. All 10 of these counties gained at least 11 and up to 14.8 percentage points on the nation. Eight of these counties are in Georgia. Table 4 presents per capita income figures for the Appalachian portion of each state. Appendix A provides measures of income, poverty, and unemployment for each county.

Within each region, including Southern Appalachia, however, uneven development occurred. The gains in per capita income have been larger in metropolitan counties than in nonmetropolitan counties. Consequently, the gap between metropolitan and nonmetropolitan counties in Southern Appalachia is slightly greater now (16.4 percentage points) than it was in 1969 (14.6 percentage points) (Table 1).

TABLE 4

Per capita personal income as a percentage of the national average for Appalachia and its state parts—1969, 1979, and 1989

Appalachian Part	Percentage of National Per Capita Income			Percentage Point Change 1969-1989
	1969	1979	1989	
Alabama	75	80	84	9
Georgia	73	80	87	14
Kentucky	59	67	63	4
Maryland	83	83	82	-1
Mississippi	61	66	65	4
New York	90	81	82	-8
North Carolina	78	80	86	8
Ohio	78	80	71	-7
Pennsylvania	91	94	90	-1
South Carolina	80	83	86	6
Tennessee	73	76	79	6
Virginia	66	76	76	10
West Virginia	76	80	74	-2
Appalachia	80	83	82	2
United States	$4,051	$9,919	$18,696	-

Source: Appalachian Regional Commission 1991: U.S. Department of Commerce, Bureau of Economic Analysis 1992.

Also, despite the phenomenal growth around Atlanta, counties in the northwest corner of Georgia have had two decades of decline in their per capita income. This has resulted primarily from a decline in wages from textile and apparel manufacturing. Four of the five counties in Appalachian Georgia with two decades of decline in per capita income are in this corner of Georgia. They contrast with 17 Appalachian counties in Georgia that have had two decades of growth in per capita income. Similarly, only one county in Alabama—Coosa County—has had two decades of decline in per capita income. It remains the poorest county in Appalachian Alabama.

The Southern Appalachian counties of both North Carolina and South Carolina have seen increases more evenly distributed. Most had two decades of increase, and none had two decades of decline. Once again, however, the rate of growth of metropolitan counties has been more rapid than that of nonmetropolitan counties; consequently, the gap between the two sets of counties is larger.

The pattern in the remaining state in Southern Appalachia, Mississippi, is different. Appalachian counties in this "sun belt" state have seen increases in per capita income from 1970 to the present. However, all counties lost in their relative per capita income in the 1980s, and three counties, all adjoining, lost in both decades.

Wearing Away in the "Rust Belt"

In contrast to the counties of Southern Appalachia, those of Northern Appalachia experienced modest growth or drastic decline in per capita income and population. The Northern Appalachian counties also exhibit a far different pattern of development. The Appalachian counties of New York, the southern tier of counties, had substantial declines—about 9 percentage points—in per capita income in the 1970s. In the 1980s, all of New York's Appalachian counties had varying degrees of recovery. Two metropolitan counties, Tompkins (Ithaca) and Broome (Binghamton), led the way. After two decades of economic restructuring and change, the counties of Appalachian New York have seen their relative per capita income decline about 8 percentage points from 1969 to 1989. Rural New York counties have had a larger decline than urban counties.

Per capita income losses have been more modest in Appalachian Pennsylvania and are distributed more evenly between urban and rural counties. The 1970s were a decade of modest increase and the 1980s a decade of decline. Losses led increases for an overall loss of 1 percentage point in relative per capita personal income from 1969 to 1989. Over the past decade, the population of Appalachian Pennsylvania declined by 3.8 percent (Appendix A). Still, Appalachian Pennsylvania remains the most populous state segment of the region with 5.8 million people, or 27.9 percent of the population of Appalachia, as reported in Table 1 in Chapter 1 (also see Appendices A and B).

Appalachian Ohio underwent a drastic decline in relative per capita income in the 1980s—9 percentage points. Contributing to this loss were severe drops in the coal- and steel-producing counties around Steubenville, where relative per capita income declined 11 to 15 percentage points for many counties, and in one case, 24 percentage points. These large declines also were frequent in the West Virginia counties of the Northern Appalachian region.

Central Appalachia

Despite the breadth and width of the Appalachian Regional Commission's geographic definition of the region, Appalachia, in the popular mind, is synonymous with Central Appalachia. This portion of the region—eastern Kentucky and contiguous portions of eastern Tennessee, southwestern Virginia, and southern West Virginia—is the area we associate with journalist Charles Kuralt's reports for CBS and other television and film documentaries. It is perceived as an area of chronic economic depression, poverty, and high human need—the "other America" that social scientist Michael Harrington uncovered in the 1960s (Harrington 1963). It is this region and this popular image that created the most unique definition of Appalachia: a transitive verb, "to Appalachianize," meaning to extract resources without benefit to the people who live in the region and to their detriment because the industry eliminates other development possibilities.

Central Appalachia is identified with coal mining, which remains a central element of the region's political economy. The 1970s brought dramatic increases in the per capita income of coal-producing counties. The energy crisis meant increased demand and higher prices for coal, increased employment, and higher wages. The coal-producing counties in Kentucky, Virginia, and West Virginia had large rises in per capita income in the 1970s and equally large decreases in the 1980s. Martin County, Kentucky, had the wildest economic boom and bust swing in per capita income, moving from 34.1 percent of the national average in 1969 to 79.6 percent in 1979 to 58.6 percent in 1989. Other counties had double-digit swings in the two decades but none so dramatic.

Many Central Appalachian counties, unlike Martin County, have no coal mining; in general, they are worse off than coalmining counties in the region. Moreover, they generally are the worst off of all counties in Appalachia. Five of the ten poorest counties in Appalachia are noncoal counties in eastern Kentucky. Appalachian Kentucky, the major portion of Central Appalachia, had an 8-percentage point increase in its per capita income ratio in the 1970s and a 4-percentage point decrease in the 1980s. During the same time, these counties had continued outmigration and showed a population decline of almost 3 percent. In 1989, Kentucky's relative per capita income was 63 percent of the national average, the lowest of any Appalachian state.

Overall, the Appalachian region lost ground on the nation in the 1980s. The region's per capita personal income compared with the national figure dropped from 83 to 82 percent. Appalachia's population grew by 1.6 percent in the 1980s compared with national population growth of 9.8 percent. Within these regional averages are high and lows. Traditionally depressed areas of the region—eastern Kentucky and West Virginia—lost much economic ground on personal income in the 1980s. Similarly, states with declining industrial bases—Ohio and Pennsylvania—also lost much ground.

On the other hand, some sections of Southern Appalachia—Georgia, North Carolina, and South Carolina—enjoyed economic growth as well as population increases. The news from other sections of the region was mixed, except for Mississippi, where chronic conditions of poverty, similar to those in Central Appalachia, got worse. Per capita personal incomes relative to the national average for 1989 are depicted in Figure 1.

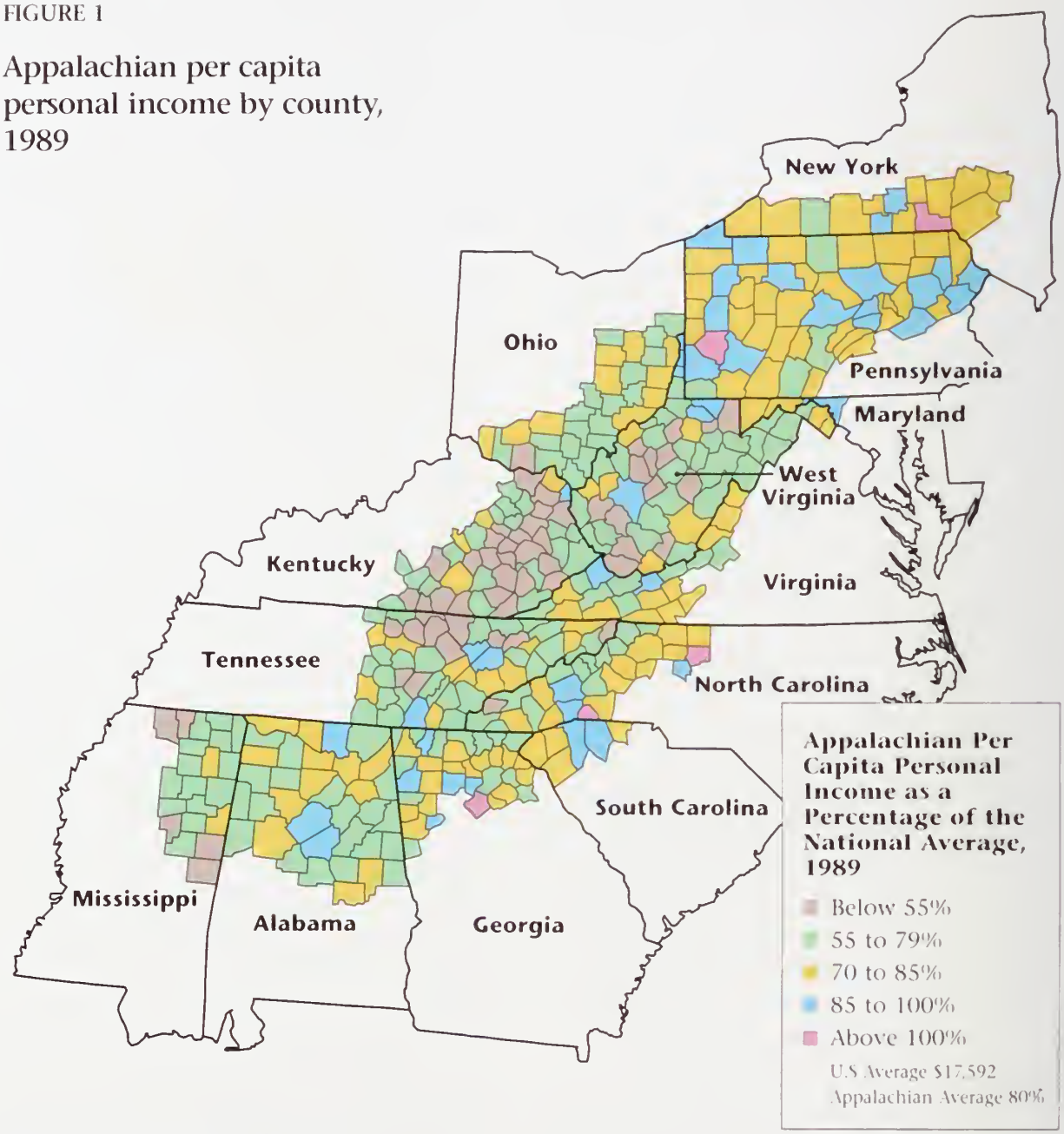
Measures of New Economic Need in Appalachia

Reports of the Appalachian Regional Commission (ARC) in 1988 suggested how changes in employment and income had created new levels of economic problems in the region. ARC ranked each Appalachian county as severely distressed, distressed, middle, strong, or very strong. Each rank is based on a combination of three measures: a 3-year average unemployment rate, per capita market income and personal income minus transfer payments, and the rate of poverty. Each of these three county measures is compared with the national rate. For example, the average 3-year unemployment rate of each county is classified in the following categories: 150 percent or more of the national figure, 125 to 149 percent, 101 to 124 percent, 76 to 100 percent, or 75 percent or less. Per capita market income is classified as below two-thirds of the national level, two-thirds to four-fifths of the national level, and more than four-fifths of the national level. The poverty rate of each county is classified in the same manner. To be labeled severely distressed, an Appalachian county must have a 3-year unemployment rate of at least 150 percent of the official national figure, per capita market income less than 67 percent of the national amount, and a poverty rate of 150 percent or more of the national rate. Very strong counties, on the other end of the economic spectrum, have measures of 75 percent of unemployment, 80 percent of income, and 75 percent of the national rate of poverty. Appendix A lists all the counties of Appalachia with their ARC ranks for 1988. According to ARC rankings in that year, 90 counties were severely distressed, 50 distressed, 237 middle, 16 strong, and 4 very strong. Figure 2 portrays the counties of the region by their economic status.

In 1992, the ARC economic ranks were calculated again to see what changes may have occurred since 1988 (Appalachian Regional Commission 1992). Initial results seemed to indicate economic improvements for many counties that were labeled severely distressed in 1988. However, on closer scrutiny, it was found that no real improvement

FIGURE 1

Appalachian per capita personal income by county, 1989



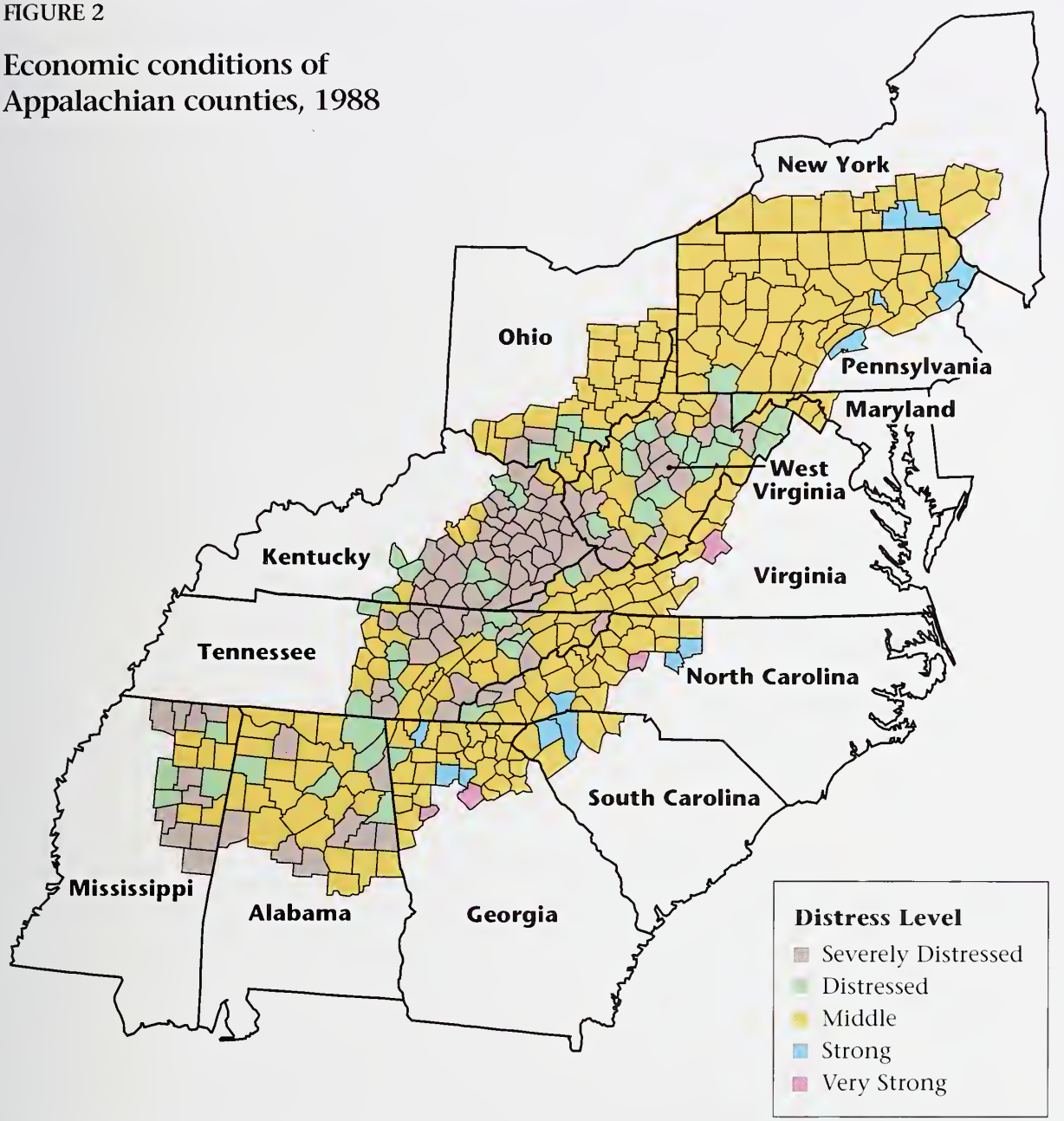
Source: Bureau of Economic Analysis, Local Area Personal Income.

occurred for many of these counties between 1988 and 1992. In fact, economic trends and the recession of the 1980s brought new levels of poverty to Appalachia that eluded detection in 1992 using traditional economic measures (ARC 1992).

In Owsley County, Kentucky, for example, one of every two people was poor and the average income in the county was only 46 percent of the nation's average, according to the 1990 census (ARC 1992). A survey of the 1990 census by the Children's Defense Fund (1992) also reported that 64 percent of the children in the county lived in poor families. Yet Owsley County's economic status appeared to have improved from severely distressed to distressed in the initial 1992 ARC ranking.

FIGURE 2

Economic conditions of Appalachian counties, 1988



Source: Couto, in press. Used with permission.

Eleven counties in eastern Kentucky, perennially the poorest region of Appalachia, and four counties in Tennessee were not ranked severely distressed in 1992 because their official unemployment rate failed to meet the criterion for severely depressed counties—150 percent of the national unemployment figure. However, because official unemployment rates do not include the long-term unemployed, the discouraged workers who give up trying to find work, and men and women who do not enter the work force because of the futility of trying to find work, the "unofficial" unemployment rates for these counties were much higher than the official rates. Therefore, the effect of using the official unemployment rate as one of three combined measures used to calculate economic rank was

to artificially inflate these counties' 1992 ARC economic ranks.

In fact, between 1988 and 1992, the situation in Central Appalachia became so bad that many counties labeled severely distressed in 1988 moved below or beyond ARC's definition of severely distressed counties, and areas of Appalachian Ohio and Pennsylvania, especially declining industrial areas, moved down in economic rank to replace them. The economic ladder now has a lower rung where no Appalachian county stood before. ARC subsequently adapted its policies and decided that counties previously ranked severely distressed would continue to be eligible under that rank despite changes in a single measure.

Appalachian Needs and Social Capital Disinvestment

Areas of Appalachia have had population increases or decreases because people move from areas of low economic opportunity to places where there is more. This population shift indicates the role of social capital, which can be defined as the goods and services we invest to produce and reproduce people in community. That is, we provide forms of social capital in conjunction with the actions of private capital to provide employment and as part of the terms of employment. Social capital—like education, housing, health care, and environmental quality—is linked to employment and income in the United States. Where there are ample employment opportunities for skilled labor, our investment in social capital is very high. Where there are few employment opportunities or a predominance of low-skilled work opportunities, our investment in social capital is very low.

Human needs of housing, education, health care, and the environment are part of the political economy of Appalachia and the nation and subsequently affect health status. The investment in these needs is a form of social capital and is made according to the investment of private capital. As the demand for labor increases or declines, so does investment in social capital. Historically, the patterns of investment are closely tied; in Appalachia, the tie is evident. Economic development and decline accompanied the development and decline of social capital forms expressed in both steel and textile "mill towns" and "coal towns." Where agriculture demanded large numbers of unskilled labor, there were sharecroppers and later migrant laborers. Both labor forces were marked by an absolute paucity of social capital in housing, education, health care, sanitation, and so forth. When the demand for labor declines, obviously wages and incomes also decline. Less obviously, social capital declines as well. Employers do not invest, directly or indirectly, in producing and expanding a work force they no longer need. Housing declines, medical services drop, education lacks support, and the environmental quality declines, as the abandoned coal towns and declining mill towns of the region testify.

All these changes suggest that social capital declines where the demand for labor declines. Investment in the agricultural, manufacturing, and mining sectors of the Appalachian economy affects investment in the employment-linked social capital—health care, housing, and education—that attracts or sustains the work force in those sectors. Similarly, disinvestment or changes in investment in production bring about changes in the investments that employers make in people. In agriculture and coal mining, for example, new investment in machinery meant less demand for labor and less social capital investment in the people displaced by new technologies. This sent a wave of migration to areas where new investment meant increased demand for labor. The shifts in private capital investments, which Reich (1991) and Fisher (1990) discuss, have their parallel in the investment or disinvestment of social capital.

Conclusion

The human problems of Appalachia are rooted in the American policies of social capital and their intrinsic relation to employment and the market. The Appalachia Leadership Initiative on Cancer—no less than any other community-based, problemsolving effort—is likely to find more resources to deal with cancer control and prevention in places with more social capital. Health promotion, like other health measures, is a form of social capital. To provide cancer prevention and control in areas of greatest need means redirecting existing forms of social capital or allocating new amounts of social capital and directing them to areas where they are needed. Community-based coalitions are a first step in collecting resources to invest in the social capital of a community.

CHAPTER 2

Action Steps

1. Use available economic and demographic information to help assess the conditions and needs of targeted counties.

2. Continue evaluating local economic measures to understand the context within which community-based coalition plans and activities take place.

3. Support community-based coalition efforts to invest in underserved areas of greatest human need.

4. Examine local economic conditions for their effect on health access (e.g., health insurance, rates of medicaid eligibility, and increased or decreased use of local health resources).

5.Examine local economic conditions for their effects on employment and earnings. Use this information to shape local priorities on cancer prevention and control.

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CHAPTER 3

Status of Health in Appalachia

Gary L. Burkett

The meaning of the term "health," like that of "Appalachia," requires examination before discussion can proceed. It would be a mistake to assume that everyone shares a similar definition of this topic. Just as Appalachia means different things to different people, there is no uniform definition of health or of what it means to be "healthy." Also, as with the definition of Appalachia, some previously dominant definitions of health have been too constricting and even have served as barriers to progressive change.

Chapter 1 emphasizes the diversity of Appalachia as a region encompassing distinctive geographic subregions and including population groups and communities with widely varying demographic, economic, and sociocultural characteristics. Couto (Chapter 1, this volume) demonstrates that the stereotypical image of a homogeneous Appalachia not only has provided a distorted portrait of the region but also has perpetuated some of the region's problems. The notion of Appalachia as a conclave of "yesterday's people"—isolated by culture as well as by geography from full participation in "progress"—often has served to justify rather than to diminish social inequalities. Programs designed to promote health in Appalachia through community initiatives need to recognize both the distinctive strengths and the unique needs of specific communities.

Similarly, we need an expansive definition of health that can contribute to effective health promotion in communities. Such a definition needs to encompass a wider range of human experience than the narrow biomedical conception of health that often dominates our thinking on the subject. This narrow conception simply juxtaposes health with disease. Disease is a pathological condition of biological organisms, but there is more to human existence than biology and more to health than the reduction of disease. Moreover, health has dimensions that are grounded in the social, psychological, economic, political, and even spiritual realms of human existence. The push for an expanded definition of health is not new, as evidenced by the World Health Organization's proposing a definition of health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" more than four decades ago (World Health Organization 1958, p. 459). However, the inadequacies of a narrow conceptualization of health have become even more apparent in recent years. Programs designed to promote health at the community level need to be based on the recognition that the state of people's health is deeply rooted in the daily conditions of their lives.

One of the assumptions underlying the Appalachia Leadership Initiative on Cancer (ALIC) is that diseases such as cancer need to be addressed through additional strategies besides the scientific quest for new forms of treatment. This assumption acknowledges the

intrinsic relationship among disease, the deeper ground of human health, and the lives of people in communities. In addition, the ALIC program is based on the assumption that there is wisdom in the community that may serve as an effective supplement—or even corrective—to the approaches that traditionally have been utilized by governmental public health agencies and academic health science centers. The description of health in the Appalachian region provided in this chapter builds on these assumptions.

This chapter attempts to integrate a comprehensive understanding of health with data about specific diseases, especially cancer, in the Appalachian region. Disease statistics are presented as one important indicator of health status, but the emphasis is on grounding our understanding of disease on the conditions of life in the region's communities. Before turning to the examination of data on patterns of disease in the region, it is necessary to debunk some common myths about health in Appalachia and to offer a perspective that is as free of misconceptions as possible. This chapter then presents and examines data on specific health problems and diseases—moving from infant mortality to the common causes of death in the region with special emphasis on cancer in its various forms and, finally, to work disability as a particularly pervasive health problem in the region. In each case, the twin objectives are to compare Appalachia with the rest of the country and to identify some of the reasons for variations in health status within the region.

Myths and Misconceptions about Health in Appalachia

As suggested in Chapter 1, it is difficult to describe accurately any characteristic of the Appalachian region without first addressing some previously promulgated and widely accepted misconceptions. Such misconceptions are so deeply ingrained in the general American consciousness that it would be a potentially disastrous oversight to ignore them in the context of describing health in Appalachia. These myths originate from the same sources that nurtured the stereotypical

images of Appalachia discussed by Couto in Chapter 1, and they are repeated and perpetuated, not only in the popular press and mass media but also in academic journals and in health professions training programs. One myth concerns an allegedly high prevalence of genetically transmitted diseases in the region. A second myth, closely related to the first, holds that the people of Appalachia are unusually handicapped by character traits and psychopathologies that are linked to the region's culture. A third myth alleges that alternative health care practices—especially folk medical practices—are especially prevalent in the region and serve as a barrier to utilization of modern medical care. Each of these myths is tied to the pervasive stereotype regarding the unique "isolation" and "backwardness" of Appalachian people. Because these misleading images are so frequently a part of the preconceptions that color people's opinions of health in the region, it is imperative that they be addressed here.

The author recalls hearing the director of a regional health department respond to a query about important health problems in his area with generalized statements about the frequent "inbreeding" that goes on in mountain communities with resultant difficult (but unspecified) hereditary diseases. The myth of Appalachia as a breeding ground for genetically transmitted diseases has been perpetuated, unfortunately, by well-meaning and otherwise knowledgeable spokespersons for the region as well as by some with less noble motives. Unfortunately, Caudill, one of the otherwise insightful and progressive advocates for Appalachia, repeatedly complained about the deterioration of the genetic stock in the mountains as the most able and ambitious people were removed through outmigration and the less able and less motivated were left to breed inferior offspring. "In some communities the blood lines are so few and intermixed that the most patient genealogist might lose his wits in attempting to unravel them. The inbreeding with its attendant genetic pitfalls contributed much in later years to the erosion of the highlander's self-reliance" (Caudill 1962, page 85). Others have suggested that allegedly pathological rates of intermarriage in the mountains have contributed to high rates of diseases ranging from Huntington's chorea and Alzheimer's disease to a wide assortment of other maladies.

As Zahorik (1989) has shown in her anthropological studies, the notion that genetically transmitted diseases (let alone nongenetically transmitted traits such as "lack of ambition") are especially prevalent in Appalachia is not based on any scientific evidence. Although there may be small kinship clusters where a particular disease is unusually common, this is certainly true in other regions of the country and in other parts of the world as well. The belief that "inbreeding" and the perpetuation of "bad genes" are somehow responsible for Appalachia's problems is a product of popular mythology that, once again, finds it more plausible to blame the people of the region for perpetuating their gene pool than to look elsewhere for explanations.

A second myth about health in Appalachia alleges that psychopathological personality traits are perpetuated by the culture of the region. As Reginald S. Lourie, M.D., expressed it in his foreword to Looff's (1971) widely read book, *Appalachia's Children*:

> *The problem is Appalachia...Dr. Looff highlights from his studies processes that are determinants of the developmental experiences and resulting personality patterns which, from generation to generation, lock in the inner forces and perpetuate self-defeating attitudes. These, combined with the problems of economics and geography, provide the basis for the resistance to change which has marked the attempts at intervention to modify the attitudes and life-style of the mountain people. This developmental process ends with what has been described as "the pride and privatism of people unable to compete outside the ancient kinships of the hollow" (pp. ix-x).*

The theory of the "psychopathology of Appalachia" was expressed, perhaps most blatantly, by a Vanderbilt University psychiatrist who reported on a study of people in West Virginia (Goshen 1970). Goshen's article, "Characterologic Deterrents to Economic Progress in People of Appalachia," was published in the *Southern Medical Journal*. The study described four distinctive classes of people in the region: the cultural primitives, the traditional farmers, the local small business group, and the more powerful entrepreneurial class. The report on the study focused on only the first two classes. The cultural primitives were described as "characterologically similar to schizophrenics" and the traditional farmers as "having character structures similar to psychoneurotics" (Goshen 1970, p. 1054). Among the traits ascribed to the cultural primitives were the following: responsibility as other people know it is a trap to avoid; religion is virtually nonexistent except for occasional local flurries of interest; they rarely see any advantage to education; and the men almost universally consume alcoholic beverages at any opportunity. The article concluded:

> *The implications of these conclusions as far as economic progress is concerned are that both groups demonstrate massive, self-defeating resistance to change. Programs of improvement, to be effective, must deal with characterologic problems in ways similar to those of the psychotherapist...In both groups of people, peculiar language problems will serve as obstacles (p. 1061).*

It is hoped that the blatant victim blaming revealed in such approaches to identifying an "Appalachian character" is obvious to all readers of this monograph. The pseudoscientific substitution of psychiatric labels for genuine understanding of the conditions of people's lives is a technique that has been used to justify social inequalities in many other contexts.

The third common myth about health in Appalachia holds that the region is especially characterized by the persistence of folk healing practices (e.g., herbal medicine) and other forms of alternative healing (e.g., religious faith healing) that have been preserved because of cultural isolation. As with other aspects of the stereotypical image of Appalachia, the notion of the region as a unique reservoir of folk and traditional healing systems has been perpetuated in the academic literature as well as in the popular culture. Although this belief would appear to be relatively benign, it plays a significant supporting role in maintaining the stereotypical concept of Appalachia's health problems. A frequent corollary to this view is that people in Appalachia are not only unusually attracted to alternative healing systems but also unusually handicapped by their adherence to such systems. Their especially stubborn adherence to traditional and folk medical systems, according to this perspective, prevents them from taking full advantage of the benefits of scientific biomedicine.

This perspective is misleading, not because it is not true that alternative healing systems persist and flourish in Appalachia, but because alternative healing systems persist and flourish everywhere (Hufford 1992). Because adherence to alternative forms of healing is commonly viewed as characteristic of only certain groups of people (e.g., certain ethnic groups, the less educated, the culturally isolated), the myth that such healing systems are uniquely prevalent in Appalachia is congruent with popular misconceptions about both alternative healing systems and Appalachia. It is true that in Southern Appalachian communities there are herbal healers whose healing practices have historic ties to traditional Native American remedies, that there is a "powwow" tradition of healing in Pennsylvania that was brought to the area by German-speaking settlers, and that there are many churches in the region that practice variations of "faith healing." These practices have attracted the attention of many folklorists and cultural preserva-

tionists with a legitimate interest in understanding and recording such varieties of folk medicine. It is also true, however, that amazing numbers of wide-ranging alternative healing practices flourish in all American communities outside of the region. The variety of "health food" stores, occult bookstores, and advertisements for homeopaths, naturopaths, iridologists, acupuncturists, and reflexologists apparent in any university community suggests that it is the highly educated and culturally cosmopolitan who are most attracted to alternative healing systems. Cavender (1992), writing about the southern part of the Appalachian region in particular, noted that "the erroneous assumptions and lingering misconceptions about the use of folk medicine" in the region have been particularly congruent with "a uniformistic view of the Appalachian South as a culturally retarded region characterized by outmoded beliefs and behaviors" (p. 170.)

To see a clear picture of the state of health in Appalachia, we need to free ourselves from these erroneous and dangerous misconceptions that distort our vision of the region. Where particular health problems are unusually prevalent in the region, we must look for causes other than genetic inbreeding, characterological defects, or overreliance on folk healing practices for explanations.

Patterns of Health and Disease in Appalachia

One indicator of people's health status is the particular pattern of diseases from which they suffer and die. Disease patterns vary greatly from society to society and have changed in our own society from one historical era to another. To a large extent, every society determines the diseases that will afflict its members and how these diseases will be distributed among particular social groups. By examining the patterns of disease, we can learn about the "social production" of health and illness. By examining patterns of disease in Appalachia, we can learn about the social arrangements that produce these patterns and about the kinds of actions that might be undertaken to improve the health of people in the region.

Limitations of Data on Disease Patterns

Examining patterns of disease requires access to data that are collected with a high degree of precision and uniformity for the entire population of interest. Unfortunately, few existing data sets meet these requirements for the Appalachian region as a whole. Although one might wish to know, for example, about the occurrence of chronic obstructive pulmonary disease in Appalachia, there is no way to determine the incidence (number of new cases) or prevalence (number of existing cases) of this health problem. To determine this with any degree of accuracy, it would be necessary for all people with this health problem to see a physician and receive an official diagnosis and for all physicians to report the diagnosis to a central data registry. Neither of these conditions is met in our current system of health care. For the most part, the best available data comprise information on the conditions that cause deaths because (1) the law requires every death to be registered with a death certificate that includes a physician's judgment about the cause of death, and (2) this information about the cause of death, is collected by all state health departments and reported to a central registry.

Nonetheless, even mortality statistics have serious limitations as indicators of the health of a population. These statistics include information only on diseases that are serious enough to cause death. They depend on a physician's judgment about the cause of a person's death, which sometimes may be based on a careful autopsy and other times may be based on a more cursory deduction. Mortality statistics often ignore the complexity of interacting diseases that may actually cause a person's demise and instead simplistically focus on identifying a single disease as the main

cause of death. In addition, because many diseases, such as cancer, frequently exist for 20 years or more between initial occurrence and eventual death, the conditions that initially gave rise to the disease may be hard to deduce at the time of death. In spite of these limitations, mortality data provide useful information for describing patterns of disease in Appalachia and illuminating some of the sources of these disease patterns.

One further limitation of the mortality statistics presented in this chapter needs to be emphasized. When mortality data are examined for geographic units as small as counties, especially rural counties with populations of only a few thousand people, annual rates can fluctuate widely from year to year because of random variations in the number of deaths that occur in comparison with the small population used as the denominator for computation of the rate. To diminish the risk of being misled by such random fluctuations when examining rural counties with small populations, most of the rates presented in the following discussion are based on a 5-year average rather than on a single year. Nevertheless, many of the data presented in the following sections—especially for units as small as rural counties—should be interpreted with great caution.[1]

Infant Mortality Rates

Among the available data, rates of infant mortality (deaths occurring before the age of 1 year) are an especially useful indicator of a population's general health status. Not only are infant deaths a particularly tragic event and a public health challenge in and of themselves, but also infant mortality rates provide evidence regarding more general public health concerns such as health care access, environmental factors, nutrition, education, and sanitation and regarding lifestyle factors such as tobacco use and alcohol consumption. For example, the fact that the United States infant mortality rate is higher than that of many other industrialized countries suggests that serious matters related to health and health care in our country are in need of much improvement.

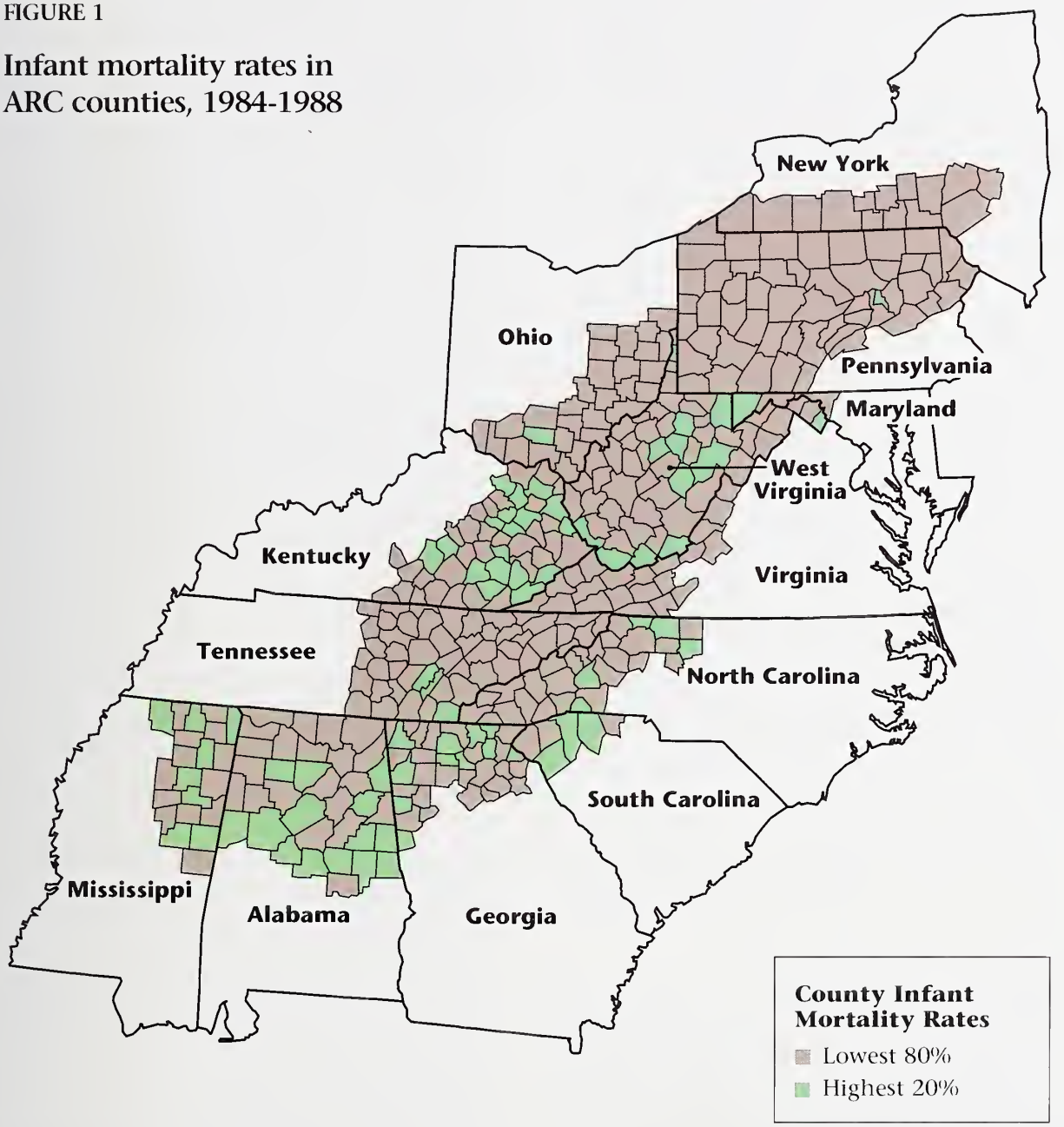
The infant mortality rate for the entire Appalachian region is currently the same as the rate for the United States as a whole. The rate of infant deaths per 1,000 live births between 1984 and 1988 for both the United States and the Appalachian region was 10.4 (see Appendix A). Significant improvements in Appalachian infant mortality in recent years provide some basis for optimism about public health accomplishments in the region over the past two decades. A recent report to the Appalachian Regional Commission (ARC) noted, "By the end of the 1980s, fewer children were born in Appalachia, but significantly more survived than in the 1960s. Four thousand infants born in 1988—who might have died in the 1960s—survived to their first birthday" (Lewis-Idema 1990, p. 7). Within the region, however, marked variations in infant mortality rates remain, with not all communities sharing equally in the progress made.

This same report notes a concern that "the number of counties with infant mortality rates above 150 percent of the U.S. average is increasing. In 1970, 70 Appalachian counties (17.6 percent of the total) had infant mortality rates greater than 150 percent of the U.S. average. During the 1980s, approximately 65 counties had such high rates, and the number fell to 57 in 1985. However, since that time, the number of counties with exceedingly high infant mortality rates has increased each year, reaching 77 by 1988" (Lewis-Idema, 1990, p. 7).

Figure 1 provides a map showing how counties with higher rates of infant mortality are distributed in the Appalachian region. The 20 percent of counties with the highest infant mortality rates in the 1984-1988 period are shown in black with the others in white. The mean county infant mortality rates for these groups are 15.2 and 9.1, respectively. It is

FIGURE 1

Infant mortality rates in ARC counties, 1984-1988



Source: HRSA.

important to reemphasize the necessity for caution in the interpretation of these county infant mortality rates. Although the rates are accurate for the years shown, a small population can produce a high rate in a county with a small number of infant deaths, and these rates can change greatly from year to year. The general patterns revealed by the map are more valid than the rates for any particular county.

The patterns revealed by the map and an analysis of the differences between counties according to their infant mortality rates show that those counties with higher infant mortality rates also have a higher percentage of people living in poverty, a lower per capita income, a higher official unemployment rate, and a lower median age. The percentage of the population classified as living in poverty, for

example, is about 23 percent for the counties with high infant mortality rates and 18 percent for the other counties. The percentage of the population receiving public assistance income is about 45 percent for the counties with high infant mortality rates and 36 percent for the others. Counties with high infant mortality rates also are more likely to be rural. Eighty-two percent of the counties shown on the map as having the highest infant mortality rates are rural. This compares with only 63 percent of the lower mortality rate counties.

Although high infant mortality rates are scattered throughout Central and Southern Appalachia, two kinds of clusters can be identified on the map in Figure 1. One cluster consists of 22 counties in Alabama and Mississippi whose most unique demographic characteristic, compared with the rest of the region, is a higher proportion of African-American citizens. The high infant mortality rates in these counties reflects the national pattern in which African-American infants die at twice the rate of white infants. In the 22 counties in Alabama and Mississippi with high infant mortality rates, African Americans constitute more than 10 percent of the population in 14 counties, more than 20 percent of the population in 9 counties, and more than 30 percent of the population in 6 counties.

These 22 counties also have relatively low per capita incomes and high proportions of their citizens living in poverty. Nine counties were listed by the Census Bureau in 1990 (U.S. Department of Commerce 1993) as having more than 20 percent of their population living under the official poverty level, and two of them had more than 30 percent of their population living in poverty. Four of the eight Mississippi counties with high infant mortality rates have an official unemployment rate greater than 10 percent. In addition, 12 of these 22 Alabama and Mississippi counties were classified in 1988 as "severely distressed" by ARC using the index described by Couto in Chapter 2 and presented in Appendix A. This cluster of counties is predominantly rural (17 of 22 counties).

The second cluster of counties with high infant mortality rates identified in Figure 1 consists of the counties extending from northern Tennessee through Kentucky and West Virginia. The most unique characteristic of many of these counties is their dependence on the coalmining economy. This cluster is also predominantly rural. Of the 32 counties in Kentucky and West Virginia with high rates of infant mortality shown in Figure 1, 28 are classified as rural. These 32 high infant mortality counties are also the counties with the highest rates of poverty, lowest levels of educational attainment, and highest levels of unemployment in the Appalachian region. More than 20 percent of the population is classified as living in poverty in all 19 Kentucky counties and in 8 of the 13 West Virginia counties. More than 30 percent of the population is classified as living in poverty in 11 Kentucky counties and in 3 West Virginia counties. Three of the counties with high infant mortality rates in Kentucky have more than 40 percent of their population living in poverty, and one of these counties has more than 50 percent. In 13 of the 19 Kentucky counties, less than 50 percent of the population has completed high school. The official unemployment rate is more than 10 percent in 22 of these Kentucky and West Virginia counties and more than 15 percent in 7 counties.

In the Appalachian region and in our society in general, the factors that contribute to a greater likelihood that infants will die in their first year are more prevalent in communities suffering from the kinds of social distress described above. According to *Healthy People 2000*, reductions in infant mortality rates will require "focus on modifying the behaviors and lifestyles that affect birth outcomes" (U.S. Department of Health and Human Services 1991, p. 364). It is suggested that health care

TABLE 1

Mortality Rates per 100,000 in the United States and the Appalachian region* by cause of death, 1988

Cause of Death	United States	Appalachian Region		
		Total	Urban†	Rural‡
All causes	871.7	1,006.3	997.7	1,024.9
Ischemic heart disease	204.9	245.5	240.6	256.2
Malignant neoplasms	195.0	219.6	220.6	217.4
Other cardiovascular disease	184.9	226.6	228.0	223.4
Other external causes	41.6	41.7	39.5	46.3
Bronchitis, emphysema, asthma	33.3	39.7	38.8	41.6
Influenza and pneumonia	31.2	34.5	33.1	37.5
Motor vehicle accidents	19.7	24.8	21.6	31.6
Infectious and parasitic diseases	19.3	15.0	15.3	14.5
Cirrhosis of the liver	10.6	9.7	9.9	9.1
Other causes	131.1	149.3	150.1	147.4

**At the time these figures were compiled, there were 398 counties designated as Appalachian: the number recently was increased to 399.*

†USDA Rural-Urban Continuum Codes 0-5

‡USDA Rural-Urban Continuum Codes 6-9

NOTE: Sums of rates for specific causes do not exactly equal rate for all causes because of rounding in calculations.

Data Source: Health Resources and Services administration, Area Resource File.

providers and individuals concentrate on the following factors:

> *Couples who wish to have more children need to know more about reproduction, conception, and the importance of reducing risks before pregnancy. For example, they should receive comprehensive risk assessments that identify health problems or unhealthy behaviors that are addressed before pregnancy, such as smoking, substance abuse, poor nutrition, family/genetic history, medical problems and chronic illness, psychosocial problems, and short pregnancy interval (U.S. Department of Health and Human Services 1991, p. 364).*

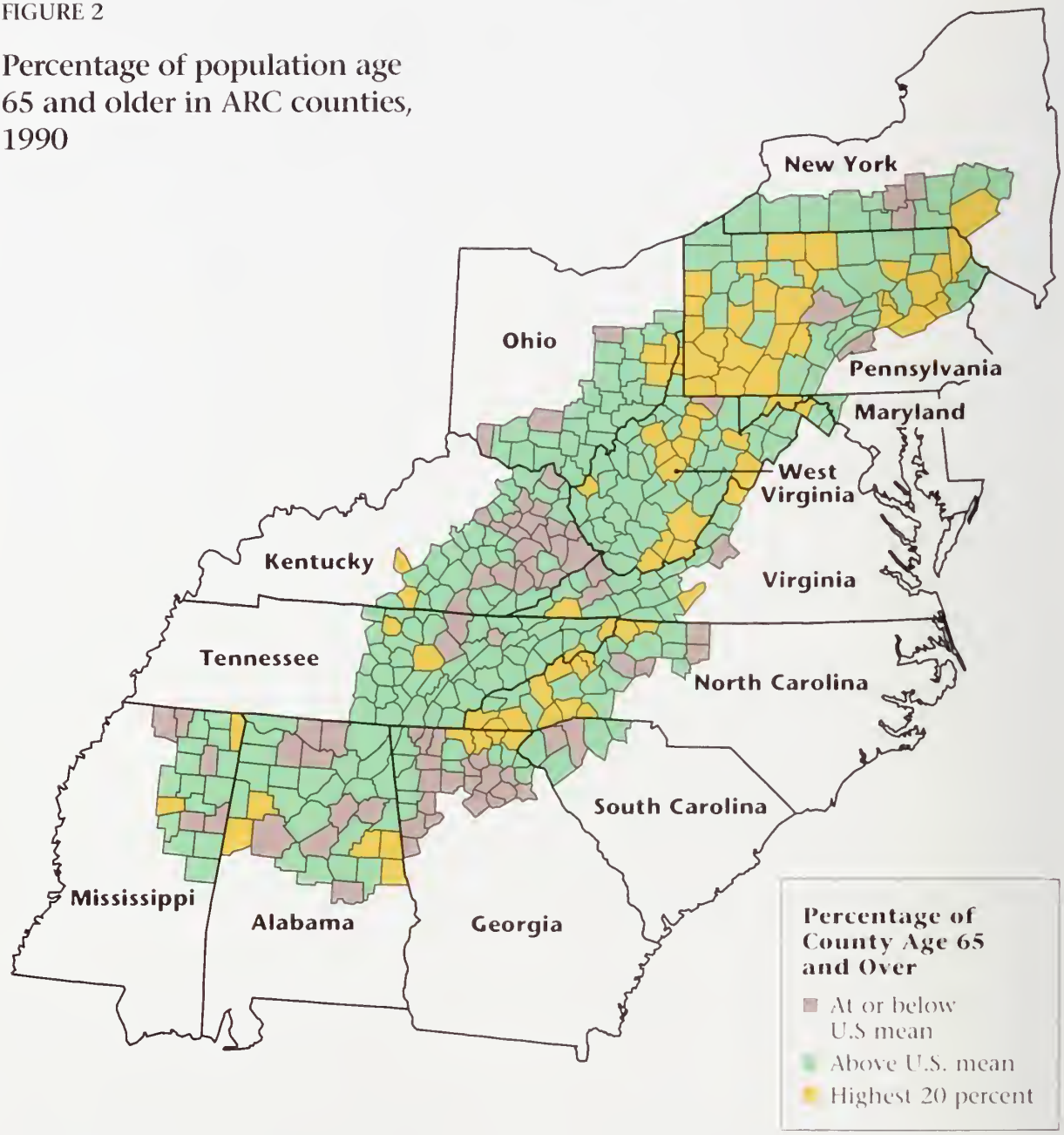
Healthy People 2000 also points out that women who receive prenatal care in the first trimester have better pregnancy outcomes than women who receive little or no prenatal care. As demonstrated in the next chapter, access to health care in general—including prenatal care—is particularly restricted in many distressed rural Appalachian counties, including many of those with higher rates of infant mortality.

Common Causes of Death in Appalachia

Table 1 compares mortality rates for the most common causes of death between the United States and the Appalachian region and, within the region, between urban and rural areas. Mortality rates are nearly universally higher for Appalachia than for the United States. Within Appalachia, rural mortality

FIGURE 2

Percentage of population age 65 and older in ARC counties, 1990



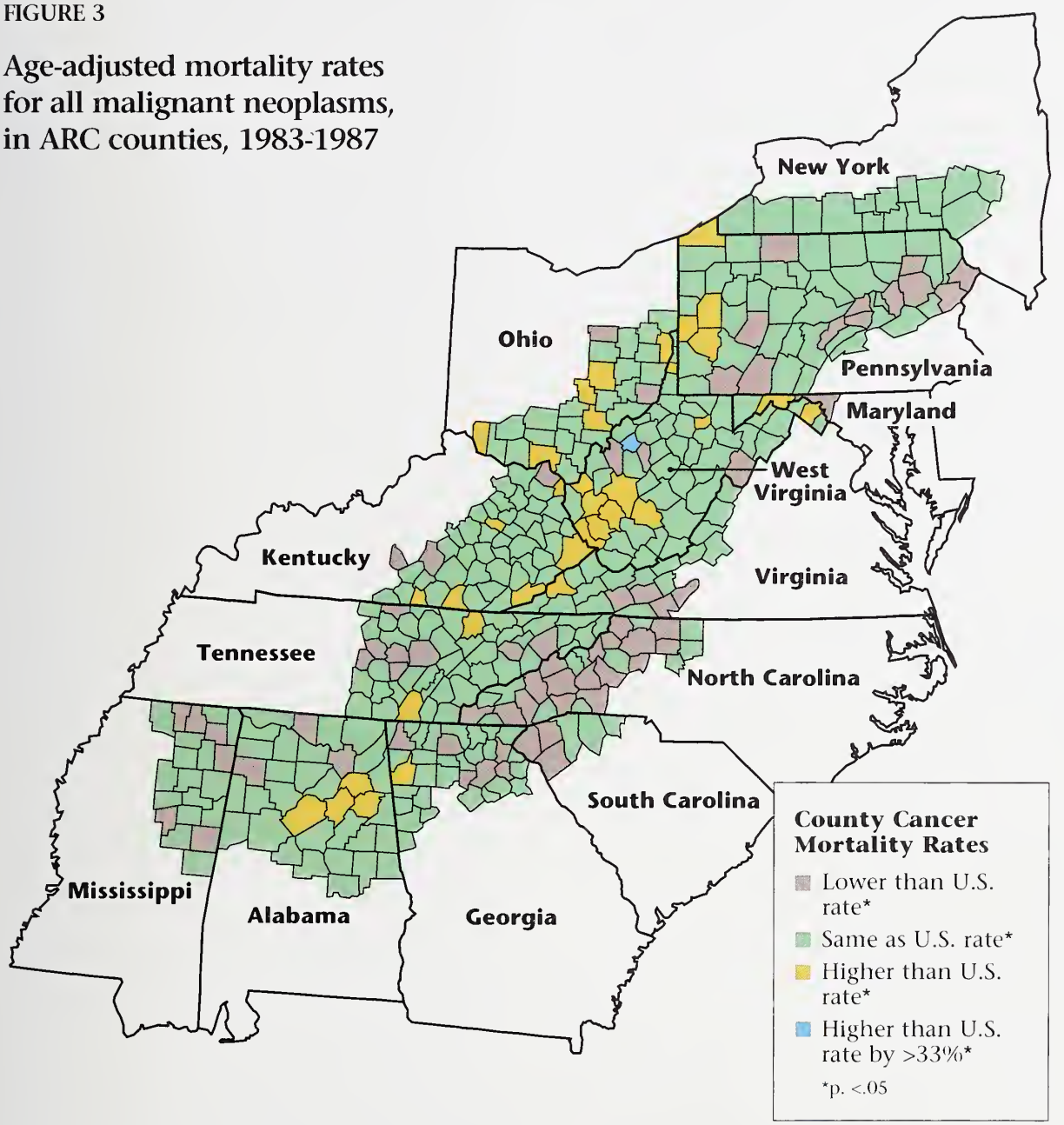
Source: HRSA.

rates are higher than urban rates for five of nine specified causes. The most important reason for the higher mortality rates in Appalachia is that the population of the region is generally older. In 1990, the median age in the United States was 32.8, compared with 34.1 in Appalachia. The percentage of the population age 65 and older was 12.6 percent in the United States, compared with 14.3 percent in the Appalachian region (see Appendix A).

Table 1 shows higher rates of mortality in the Appalachian region compared with the nation as a whole from all causes except infectious and parasitic diseases and cirrhosis of the liver. The highest single percentage difference is in deaths from motor vehicle accidents—a particularly prevalent cause of death

FIGURE 3

Age-adjusted mortality rates for all malignant neoplasms, in ARC counties, 1983-1987



Source: NCI.

in rural communities where people tend to drive many more miles on less safe roads. The three leading causes of death in both the Appalachian region and the nation—ischemic heart disease, malignant neoplasms, and other cardiovascular diseases—account for more than two-thirds of all deaths in the region. The greatest differences between the Appalachian and national rates are for ischemic heart disease and for other cardiovascular diseases.

Maps displaying the variations in mortality rates for many causes of death in Appalachia would look very much like maps showing variations in age. Figure 2 shows how different parts of the region differ with respect to age by presenting the percentage of the population age 65 and older. Northern Appalachia,

in particular, has many counties with a relatively high proportion of elderly people. Many counties in West Virginia and many Blue Ridge Mountains counties in North Carolina, which have attracted large retirement populations, also have a high proportion of elderly people. The presence of large elderly populations with their more intensive requirements for health care has obvious implications for the needs for health care services in these areas.

Cancer Mortality in Appalachia

For this examination of patterns of mortality from cancer in Appalachia, we are fortunate to have access to age-adjusted rates. Such rates are calculated through a process that compensates for variations in the ages of the populations being examined by statistically adjusting the rates to a standard population. Figure 3 displays the distribution of overall cancer mortality rates for the region for 1983-1987 based on adjusting all county populations to a 1970 standard population.[2] The result of this process is to permit examination of possible causes of cancer deaths other than age.

The procedures used to produce the data in Figure 3 also include a more reliable method for determining whether variations in rates between counties are likely to be "true variations" or variations that can occur caused by chance alone.[3] Using this procedure, county cancer mortality rates are determined to be lower or higher than U.S. rates. In addition, counties with a rate that is statistically significant (nonoverlapping 95-percent confidence intervals) and more than 33 percent higher than the U.S. rate are given a special classification. These categories are displayed in Figure 3.

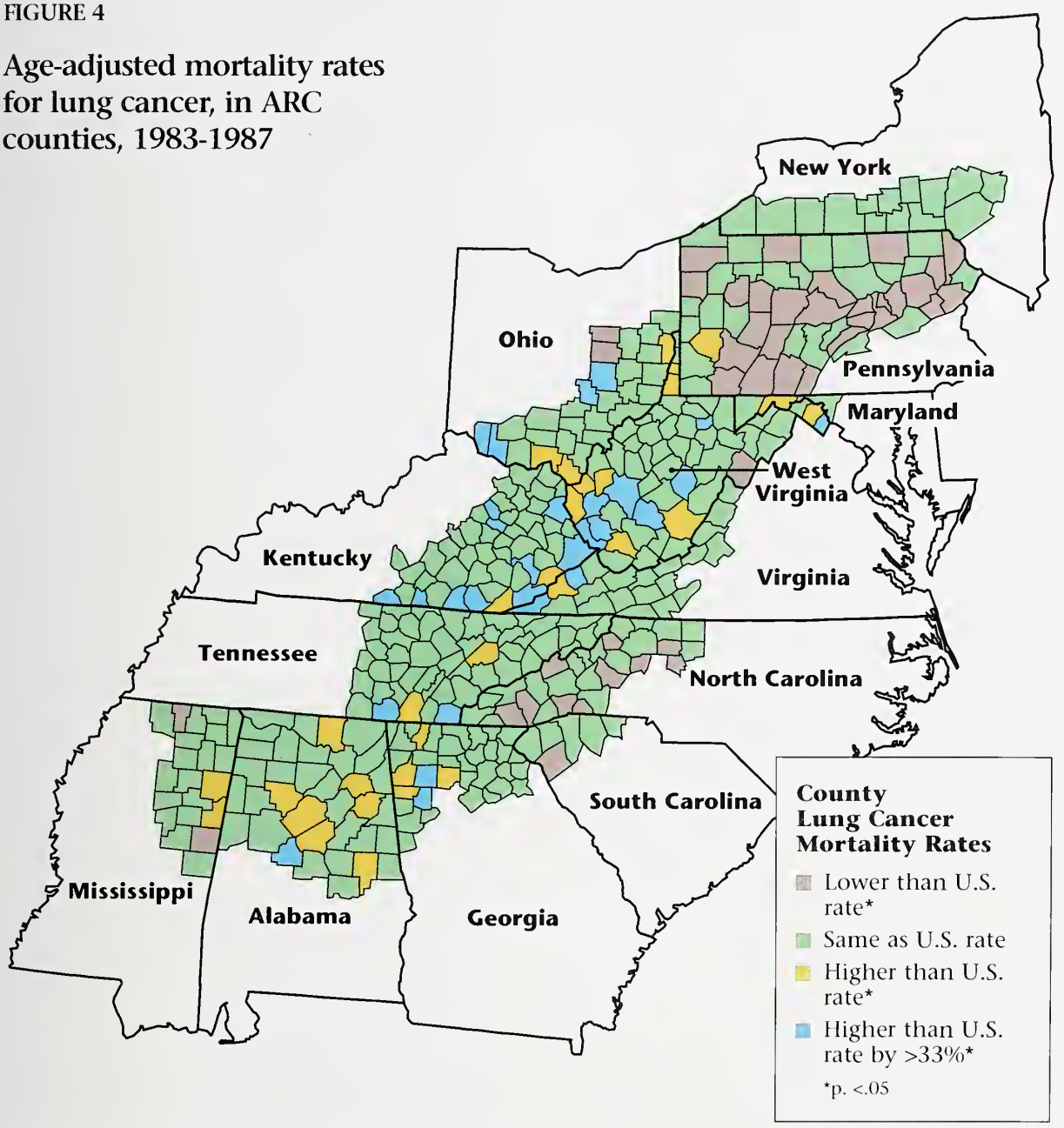
Of the 398 counties in the Appalachian region, 67 have an age-adjusted cancer mortality rate that is lower than the U.S. mean, and 37 counties have an age-adjusted rate higher than the U.S. mean.[4] One county, Wirt County in West Virginia, has a cancer mortality rate that is significantly higher than the U.S. mean by more than 33 percent. These data suggest that when all forms of cancer are considered together—and when the data are adjusted for the effects of age differences—cancer is a problem of about the same magnitude in Appalachia as it is in the rest of the United States. The exception to this generalization is the string of counties beginning in Alabama and extending along the Cumberland Mountains from Tennessee, through Kentucky and West Virginia, and into Ohio and western Pennsylvania where cancer mortality rates are significantly higher than in the rest of the nation. On the other hand, a chain of counties beginning in Virginia and continuing along the western side of the Blue Ridge Mountains into South Carolina and Georgia appear to have cancer mortality rates that are lower than expected.

There is an association between overall cancer mortality rates and poverty. A greater proportion of Appalachians living in poverty reside in high cancer rate counties than low cancer rate counties (21 percent vs. 16 percent, respectively). Twenty-two percent of the high cancer rate counties were classified by ARC as "severely distressed" in 1988 (about the same as the region as a whole), but only 10 percent of the counties with low cancer rates were classified as such (Appalachian Regional Commission 1992). However, for mortality from all forms of cancer, the counties with low rates are more rural than are the counties with high rates. Seventy-three percent of low cancer rate counties and 43 percent of the high cancer rate counties are classified as rural.

The map provided in Figure 4 shows variations in 1983-1987 age-adjusted mortality rates for the form of cancer that is the most common cause of death—lung cancer. In 1990, lung cancer accounted for 28 percent of all cancer deaths in the United States—more than twice as much as the second most common cause of cancer mortality, colorectal cancer (U.S. Department of Health and

FIGURE 4

Age-adjusted mortality rates for lung cancer, in ARC counties, 1983-1987



Source: NCI, State Cancer Control Map and Data Program.

Human Services 1991). The map shows that lung cancer is a particularly prevalent problem in Central Appalachia, especially in many of the Kentucky and West Virginia counties that were previously shown to have high rates of infant mortality as well. *Healthy People 2000* states that "90 percent of the lung cancer cases in men and 79 percent in women are attributable to cigarette smoking" (U.S. Department of Health and Human Services 1991, p. 141). The Kentucky Department for Health Services (1991) reports that the Appalachian areas of the state have the highest proportion of cigarette smokers: 29 percent of adults in Kentucky currently smoke, and in some regions of the state this figure is as high as 43 percent. To the extent that tobacco use is associated with the kinds of low-income popu-

lations that also have been shown to be associated with high rates of infant mortality, the resemblance between Figure 4 and Figure 1 can be explained. Lung cancer also has been shown to be associated with exposure to radon decay products and other environmental and occupational hazards such as asbestos (U.S. Department of Health and Human Services 1991).

The Appalachian counties with lung cancer rates that are significantly higher than the U.S. mean have a higher percentage of their populations living in poverty, lower levels of educational attainment, and a lower percentage of their population older than age 65 than the counties with significantly lower lung cancer rates. Of the 34 counties that have a lung cancer mortality rate greater than 33 percent above the U.S. mean, 79 percent are rural and 53 percent were classified by ARC as "severely distressed" (Appalachian Regional Commission 1992).

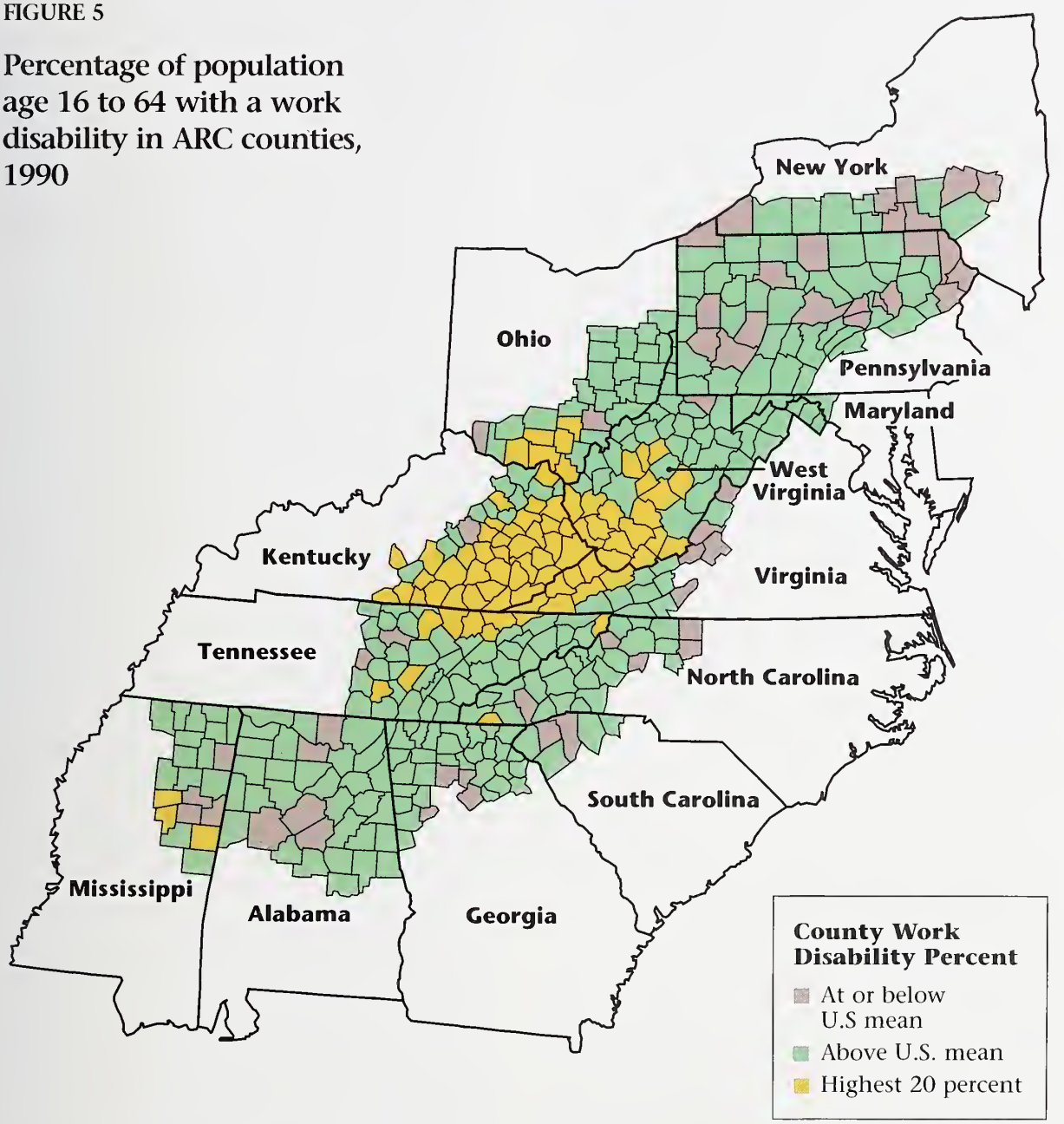
Other forms of cancer show different patterns of variation within the Appalachian region. For example, colorectal cancer, the second leading cause of cancer death, seems to be a greater problem in Northern Appalachia than in other parts of the region. Twenty-three Appalachian counties have age-adjusted colorectal cancer mortality rates significantly higher than the national rate. Eleven of these are in Pennsylvania, six in Ohio, two in New York, and one each in Maryland, South Carolina, and West Virginia. Twelve counties significantly exceed the national colorectal cancer mortality rate by more than 33 percent. These counties include Bedford, Cameron, Elk, Juniata, Lackawanna, Montour, and Potter counties in Pennsylvania; Cortland and Delaware counties in New York; Athens and Scioto counties in Ohio; and Cherokee County in South Carolina. Eighty-two Appalachian counties have a colorectal cancer mortality rate significantly lower than the national rate. The Appalachian counties with a high colorectal cancer mortality rate have a higher level of educational attainment, a lower percentage of their population in poverty, and a smaller percentage of their population who are African American than the counties with low rates. None of the 23 counties with a high rate of colorectal cancer were classified by ARC as "severely distressed" in 1988 (Appalachian Regional Commission 1992).

Healthy People 2000 notes the potential role of a low-fat, high-fiber diet for decreasing the incidence of colorectal cancer (U.S. Department of Health and Human Services 1991). It also emphasizes the importance of early detection efforts and of applying state-of-the-art therapy for decreasing colorectal cancer mortality.

Seven Appalachian counties have age-adjusted breast cancer mortality rates significantly higher than the national rate, and three of these significantly exceed the U.S. mean by more than 33 percent. These three counties are Schoharie County in New York, Clermont County in Ohio, and Ohio County in West Virginia. Fifty-seven counties have age-adjusted rates of breast cancer mortality lower than the national rate. Breast cancer mortality in Appalachia has a direct relationship with socioeconomic status, with the counties with high rates having higher per capita income and higher levels of educational attainment than the counties with low rates. The counties with the lower rates of breast cancer also have a higher percentage of their population who are African American than the counties with the higher rates. None of the counties with high breast cancer mortality rates were classified by ARC as either "distressed" or "severely distressed" (Appalachian Regional Commission 1992). The higher prevalence of breast cancer among higher socioeconomic groups and among whites in Appalachia is consistent with national patterns. Although overall rates for breast cancer are lower in the region than nationally, data prepared for the University of Kentucky (see Figure 1, Chapter 13, this monograph) show

FIGURE 5

Percentage of population age 16 to 64 with a work disability in ARC counties, 1990



Source: U.S. Department of Commerce, 1993.

that the breast cancer mortality rate has been rising rapidly in Central Appalachia compared with the rest of the United States. *Healthy People 2000* emphasizes the importance of early detection—particularly through screening mammography—for decreasing breast cancer mortality (U.S. Department of Health and Human Services 1991).

Nine counties in the Appalachian region have age-adjusted mortality rates for cancer of the uterine cervix that are significantly higher than the national rate, and all nine of these counties exceed the U.S. rate by more than 33 percent. These counties are Jefferson and Madison counties in Alabama; Pike County in Kentucky; Lowndes and Tishomingo counties in Mississippi; Jackson County in Ohio; Centre County in Pennsylvania; and Kanawha

and Mingo counties in West Virginia. Fifteen counties have rates of cervical cancer mortality that are significantly lower than the U.S. rate. The counties with high rates have higher proportions of their populations living in poverty. The African-American population of the 9 counties with high rates of cervical cancer mortality averages 10.8 percent of the total population, compared with only 1.6 percent in the 15 counties with low rates. None of the 15 counties with low rates of cervical cancer mortality were classified as "distressed" or "severely distressed" by ARC in 1988, but 3 of the 9 counties with high rates were so rated. There does not appear to be a relationship between cervical cancer mortality and rural/urban county classification in Appalachia (Appalachian Regional Commission 1992). The association between cervical cancer and low socioeconomic status and the higher rate among African Americans than among whites in the Appalachian region are consistent with national data.

Work Disability as an Appalachian Health Problem

To be "work-disabled"—limited or unable to work because of a health problem—is to suffer a major challenge to one's well-being. For many people, being unable to work means being unable to keep one's self and family out of poverty. In addition, work is a highly valued activity in our society, and what one does for a living is a major part of one's identity and sense of self-respect. Figure 5 shows how rates of work disability for people age 16 to 64, the prime working years, are distributed across the Appalachian region. Counties are classified as being at or below the U.S. mean or above the U.S. mean, with an additional category for the 20 percent of counties with the highest rates of work disability.

In contrast to the mortality rates related to specific diseases previously discussed in this chapter, measures of rates of work disability provide a more generalized indication of health. Although work disability may be connected with a wide variety of diseases—and in many cases the connection with a particular disease may be medically ambiguous—to be work-disabled is certainly to be in ill health. Work disability is a product of an individual's capabilities and the employment opportunities available in a particular community as much as of the presence of a diagnosable medical disease or injury

Figure 5 shows that work disability is a particularly prevalent health problem in Appalachia—particularly rural Appalachia. Northern Appalachia has the highest proportion of counties with work disability rates that are equal to or below the U.S. mean, and these tend to be clustered around Pittsburgh and Erie in western Pennsylvania, the Delaware River Valley in eastern Pennsylvania, and Binghamton, New York. In Central and Southern Appalachia, metropolitan counties are almost exclusively those with lower rates of work disability such as the suburban counties in Atlanta, Georgia; the suburban counties of Birmingham and the Huntsville area in Alabama; Greenville and Spartanburg counties in South Carolina; and the counties near Winston-Salem, North Carolina.

On the other hand, there is a striking and large cluster of counties with especially high rates of work disability, which includes the northern Tennessee counties, the vast majority of the Kentucky counties, and significant numbers of counties in Ohio, Virginia, and West Virginia. Again, many of these counties previously have been shown to have higher rates of infant mortality and cancer mortality—especially for lung cancer. The web of poverty, disease, unemployment, and work disability is both complex and strong. Many disability claims, as in black lung benefits (Smith 1981), are related to work; disease and injury can profoundly limit a person's ability to work; and unemployment itself is a major risk factor for illness (Brenner 1983).

Conclusion

A historical or cross-national perspective demonstrates that societies have a great deal to do with determining how their members will get sick and how they will die. Societies also determine how resources for disease prevention and care of the sick will be distributed among their members. This chapter gives some indication of where Appalachian communities fit into the contemporary distribution of health and sickness in American society.

With the exception of a few diseases that are associated with affluence, a relationship between a wide variety of indicators of poor health status and low income levels has been demonstrated among the people of Appalachia. The causal relationships between wealth and health are undoubtedly complex, so that lower income groups may experience a combination of decreased access to health care, increased risk to occupational and environmental hazards, and a greater tendency toward lifestyle habits that correlate with a low sense of control over one's destiny. There is no question, however, that poverty is dangerous to your health.

Although concentrating on Appalachia as an identifiable geographic region, this discussion has emphasized both (1) the impressive variation that exists within the region and (2) the continuities that exist between the problems experienced by people in the region and the problems experienced by other population groups in our nation. If anything is unique about Appalachia, other than the stereotypical image developed and maintained in the wider culture, it may be the way that the region isolates and magnifies so many of the problems and potential solutions that are more generic to American society.

Notes

1. An example might be helpful for illustrating the hazards of drawing conclusions from rates based on small populations. For example, say county A and county B each has a population of 10,000. In 1 year, four people die from disease X in county A, and six people die from the same disease in county B—an occurrence that could easily happen because of chance alone. Because most mortality rates are conventionally reported as number of deaths per 100,000 population, the mortality rate from disease X would be 40 for county A and 60 for county B. In addition, because the 50-percent higher rate in county B is caused by a difference of only two deaths, it would be hazardous to draw any conclusions from such small numbers. In the following year, the relative numbers of deaths in these two counties would probably be very different.

2. The State Cancer Control Map and Data Program was developed through the Early Detection Branch of the Division of Cancer Prevention and Control and the Clinical Epidemiology Branch of the Division of Cancer Etiology of the National Cancer Institute. The Division of Chronic Disease Control and Community Intervention of the Center for Chronic Disease Control and Community Intervention, Centers for Disease Control and Prevention, also was involved in the programming. The American Cancer Society provided additional assistance in several technical aspects of program development as well as financial support. The program (which is "user-friendly") is available to the public from the National Technical Information Service (NTIS), Research Services Department, 5285 Port Royal Road, Springfield, VA 22161, telephone (703) 487-4650.

3. NCI's State Cancer Control Map and Data Program calculates 95-percent confidence intervals for each county rate and determines that the county rate is significantly higher or lower than the U.S. rate if the confidence interval does not overlap the U.S. mean. This procedure of accessing statistical significance enhances the probability that observed differences in rates are not caused by random variation. On the other hand, this procedure means that a rural county with a small population would have to produce an extremely deviant rate in order to achieve statistical significance.

4. The data provided are based on a total of 398 Appalachian counties. The number was recently increased to 399.

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CHAPTER 3

Action Steps

1. Use a broad definition of health, such as that adopted by the World Health Organization (WHO), where health is seen as a state of complete physical, mental, emotional, and social well-being and not merely the absence of disease or disability.

2. Support efforts to improve tracking systems and data collection in your local area to better measure the health status and needs of local residents.

3. Collect measures of local health status. Identify health trends. Identify gaps in the measures.

4. Compare local health status, including cancer, with state and national measurements.

5. Establish a health profile of your area, and place cancer within it.

6. Identify cultural assumptions about local health practices and beliefs within your coalition, and address their foundation, accuracy, and validity.

7. Assess how the knowledge, attitudes, and behaviors of people in your community affect their cancer risks.

CHAPTER 4

Health Care Services in Appalachia

Bruce Behringer

Addressing cancer control and prevention issues in a community has two related paths. First, a community group must learn how people's knowledge, attitudes, and behaviors affect their cancer risk and susceptibility. Second, a community must assess the availability and accessibility of health system resources and programs needed to address cancer control, care, and prevention.

Overview of Rural Health

The vast majority of the land area and population of Appalachia is classified as rural. Regardless of whether one uses population density or location outside a standard metropolitan statistical area to define rurality, two-thirds of Appalachia's counties and population are characterized as rural, compared with one-fourth of the total U.S. population (U.S. Congress, Office of Technology Assessment 1990).

The health care system in Appalachia manifests the national problems with rural health care. Despite the region's health care services being spread across 13 states, general characteristics of the system, health care providers, and financing difficulties in Appalachia reflect common characteristics of national rural health.

► Many Appalachian communities suffer from the maladies of dependence on single industries, persistent poverty, and higher concentrations of the uninsured, underinsured, and elderly (Behringer 1992).

► Appalachian health care providers are generally solo primary care physicians—a disappearing breed. The existing general and family physicians are older (Barnett and Midtling 1989), and younger physicians increasingly are electing to become specialist physicians (Kassebau and Szenas 1992).

► Financing of health services in rural areas traditionally has shown a pattern of lower costs and lower wages, inevitably being factored into resulting lower reimbursement for services. This places strains on financing new buildings, equipment, and service programs; makes practice opportunities less competitive for primary care providers; and does not recognize the extra costs and lack of economies of scale inherent in rural operations.

Each of these factors negatively influences the ability of a community health care system to promote and sustain cancer prevention and control efforts. All in all, however, the vibrancy and resilience of communities to adopt new and innovative approaches as well as the ongoing commitment and sacrifice of their care providers have kept community health care systems afloat during hard times. This is not a new phenomenon. It has been traced through the legend of individuals like the doctors on horseback, through organizations like the Frontier Nursing Service, and through developments like the Appalachian Regional Hospital system and collective actions of consumers such as the United

Mine Workers of America (UMWA) Welfare and Retirement Fund.

Health systems in Appalachia that have not "stayed afloat" generally suffer from two major contributing characteristics: (1) problems of patient access to health care systems, some directly related to financing of care; and (2) the lack of health care professionals. Each characteristic is described below along with examples of innovative solutions that have been generated to address it.

Accessibility to Health Services and Financial Issues

The shortage of health professionals in Appalachian counties obviously affects the availability of care. This shortage influences all in the total county population equally. However, another important dimension of health care—accessibility—more often affects the poor, the uninsured, and the elderly. This section discusses the problems of accessibility in Appalachia and some national, state, and local responses.

A 1989 report to the Appalachian Regional Commission (ARC) estimated that between 1.2 million and 2.6 million residents (or up to 13 percent) of the region are medically indigent (Swartz and Holahan 1989). The variance in the estimate indicates the uneasiness that many have with the subject of medical indigence. It is hard to quantify but very easy to qualify.

Medical indigence has many roots, including poverty, disability, underemployment, and unemployment. Medical indigence also has many consequences. Limited financial resources affect people's ability to obtain expensive health care and to purchase needed medications for illnesses. People must make difficult decisions regarding paying for health care out of limited living expenses—decisions

that too often include choosing not to receive health services, delaying care when sick, not seeking preventive care, or failing to adhere to prescibed treatment protocols. From the patient perspective, medical indigence is defined by a series of "no-win" discrete personal choices.

From a health care system's viewpoint, medical indigence describes the situation of the portion of the population without adequate resources to pay for care. In social policy circles, medical indigence results in indigent care, charity care, bad debt, or uncollectible accounts. Throughout the country, the shortfall of resources costs providers billions of dollars in lost revenues, and it forces collection policies, which too often result in "cash payment only" signs in waiting rooms.

Local invisible systems of care for this group may include charity care provided and written off by emergency rooms and local providers, long trips to state-sponsored teaching hospital clinics, and services from local health departments, free clinics, and community health centers when available. No one can guess the amount of care not being provided to the underserved, part of the 40 percent of health care conditions that go unattended each year (National Center for Health Statistics 1989), because no one can calculate the amount now given. The amount and organization of community resources vary remarkably, but they are too often in short supply and lacking many characteristics of good health care.

Much of the discussion about reforming health care systems and distributing resources follows a basic set of principles and beliefs about health care. All health care systems have two missions: to promote good health and prevent sickness and to treat illness. Integrated prevention and treatment services understandable to the consumer should be available through multiple points of access for patients.

Key characteristics of health care services should be promoted, particularly their comprehensiveness, continuity of care, efficiency, and effectiveness. A continuum of services for residents should be integrated from a patient perspective. Table 1 describes such a continuum of services related to cancer prevention and treatment, which should be available to all residents. Although all rural communities may not to be able to support all these services financially, it is important that "systems linkages" with other communities, including those in metropolitan areas, be established and maintained for more complex services. For example, some local hospital services (secondary care) may be available, but special cancer treatment facilities (tertiary care) may be located in major cities outside the community.

The sustainability of health care systems has both an internal community and an external state and national dimension. Internally, communities must be supportive of local providers and use their services. Rural residents in Appalachia suffer from the same problems identified in the national trend of rural residents using metropolitan health services; many times these problems leave local providers and hospitals with limited financial means to sustain themselves. Already suffering from a lack of economy of scale in practice (e.g., higher prices for purchasing smaller quantities of medical supplies), these operations are often close to collapse and simply do not replace services or health care providers as they are lost. This reduces access to emergency and obstetrical services, impacts access for less mobile and often low-income populations, and hampers the ability of communities to attract and maintain physicians and other providers (U.S. Congress, Office of Technology Assessment 1990).

External forces also encroach on the capacity of rural health systems to survive. Already faced with greater degrees of medical indigence, rural areas also are subject to reduced reimbursement rates from public and some private insurers simply because they are rural. Recently, rural hospitals have been under

TABLE 1

Cancer prevention and treatment services of the health care system

Service	Example
Health Promotion and Education	Breast Self-Exam Instruction, Smoking Cessation Classes, Nutritional Counseling
Disease Prevention	Asbestos Removal, Safe Water Programs
Primary Care	
Screening and Early Detection	Colorectal Screening, Mammograms, Pap Tests
Case Management	Coordinating Cancer Treatment Services for Patients
Emergency Services	Episodes of Acute Problems
Specialty Consultation	Oncology Diagnosis and Treatment
Hospital Care	
Outpatient Treatment	Chemotherapy and Radiotherapy Treatments
Inpatient Treatment	Surgery
Rehabilitation	Physical and Occupational Therapy, Home Health Care

attack for providing operations and care for certain diagnosis categories because marginally poorer outcomes are generally found in facilities treating smaller numbers of cases (Keeler et al. 1992). Overall, rural providers have been the targets of takeovers and buyouts by hospital and health maintenance organizations, depriving the local community from any sense of control and responsibility for their health systems.

There is no central database of information on the numbers and types of health care practices that exist in Appalachia. The basic backbone of primary care has been private solo or group practice physicians. The University of North Carolina studied a number of types of subsidized primary care organizations, including Appalachian providers (Sheps et al. 1983). That study also describes comprehensive health centers, organized group practices, primary care centers, and institutional extension practices.

Both private and subsidized practices are affected by federal programmatic efforts. With nearly 35 percent of all health care expenditures being paid by government in 1990 (National Center for Health Statistics 1992), the Health Care Financing Administration and the Public Health Service have had a record of inconsistent contradictory actions on support of rural health services. For example, programs positively influence distribution of providers who are negatively affected by lower rural reimbursement rates. These rates have a particularly significant impact on Appalachia, which is highly dependent on medicare (for the elderly and disabled) and medicaid (for the poor) payments to sustain local health care systems.

Health care financing actions have consistently penalized rural hospitals and practitioners for being "low-cost providers" through lower reimbursement payments than those received by metropolitan hospitals. On the other hand, rural providers have been the beneficiaries of specially targeted health systems development and financing initiatives. Shortages in primary care providers and low rural reimbursement rates prompted Congress to approve the Rural Health Clinics Act in 1978.

Appalachian counties are among the leaders

in receiving cost-based reimbursement for medicare and medicaid services in rural shortage and underserved areas. Pivotal in the 1978 legislation was the understanding that physician assistants and nurse practitioners could become effective rural health care providers if state medicaid programs were allowed to reimburse for their services. Therefore, Congress made rural health care a required service in all state medicaid plans, required rural health clinics to employ physician assistants and nurse practitioners at least 60 percent of the time in patient care (later reduced to 50 percent), and required reimbursement that would at least cover the costs of providing services. This reimbursement enabled a number of rural communities throughout Appalachia to establish freestanding clinics. The vast majority of them continue to provide needed services and represent a significant source of primary care and screening for cancer prevention and control services.

The federal attempt in 1983 to contain costs led to significant cuts in payment rates through implementation of the prospective payment system for hospitals. This system, which uses a formula based on resources needed to provide services according to diagnosis, created an urban-rural differential in standard payment rates. Consequently, this prospective payment system has had the net effect of closing a number of rural hospitals, has made others financially marginal, and has forced still others to revise their mission significantly. Cancer control and treatment efforts have become more regionalized because they are costly, and many rural hospitals can not afford to continue them. New federal efforts to support rural hospitals financially and help them define their mission and mix of services have promoted demonstration of new models (like the Essential Access Community Hospital/Rural Primary Care Hospital Program in New York, North Carolina, and West Virginia) and provided fiscal protection for key types of hospitals (medicare-dependent hospitals, rural referral centers, and geographic reclassification).

With the trend of new health professionals choosing specialties rather than primary care careers, Congress adopted the Resource-Based Relative Value Scale as a means of improving reimbursement for primary care services while reducing payments for more specialized procedures (Physician Payment Review Commission 1992). The scale was enacted in 1992, and the long-term impact could help rural practitioners' bottom lines and reduce the impression of medical students that financial security can not be attained in rural practice.

Access to health care services locally continues to be a major issue for federal and state policymakers. One approach, the expansion of community-based systems of care, continues to be promoted. One of the most successful and common approaches in Appalachian communities has been the community health center (CHC) and migrant health center (MHC) program. After a moribund period in the 1980s, CHCs were targeted for a growth spurt by the Bush and Clinton administrations in the 1990s.

Initiated during the "War on Poverty" of the 1960s, community health centers have played a significant role in Appalachian communities organizing their own health systems. Eighty-five percent of Appalachian counties are designated as medically underserved areas, the criterion for eligibility for CHC assistance (unpublished data, U.S. Public Health Service, Bureau of Primary Health Care). Nearly half, or 162 Appalachian counties, are currently served by CHCs. Table 2 indicates a large federal investment in the Appalachian region (approximately 13 percent of all national grant funds). The more than 425,000 persons served generally are medically indigent or have medicare or medicaid insurance.

The community health centers represent efforts at local community development and health systems development. Each center has a community board of directors that is respon-

TABLE 2

Federal investment in the Appalachian region, 1992

Appalachian Part	Total Appalachian Counties*	Number Designated Medically Underserved	Number with Community Health Centers	Total Percentage Designated Appalachian Counties with CHC Programs	FY 1992 CHC/MHC (only) Grant Dollars	1991 CHC/MHC Users
Alabama	35	34	18	53	$5,095,778	72,249
Georgia	35	27	7	25	1,105,416	12,681
Kentucky	49	43	12	28	4,296,529	37,412
Maryland	3	3	2	67	410,331	4,134
Mississippi	20	19	8	42	3,247,927	21,770
New York	14	9	2	22	533,332	5,468
North Carolina	29	25	4	16	1,630,850	6,455
Ohio	29	26	12	46	6,053,881	34,662
Pennsylvania	52	40	19	47	5,931,632	90,656
South Carolina	6	6	1	17	567,332	1,285
Tennessee	50	49	31	63	5,477,669	47,511
Virginia	21	19	8	42	1,563,191	21,496
West Virginia	55	49	38	77	10,231,602	111,558
Total	398	349	162	46	46,145,470	467,337

*One county was added after these figures were compiled.

Data Source: Health Resources and Services Administration, Bureau of Primary Health Care 1992

sible for center operations and finances. Each follows the principles of primary care and prevention, seeking 8to provide personal health services as well as developing community outreach programs. Each offers a schedule of reduced fees for low-income patients. Each is mandated to link with other health and human service organizations in the community to build a true system of care for its patients. After diagnosing community needs, many CHCs have developed special programs for migrant agricultural workers, the homeless, public housing project residents, and persons with AIDS as well as comprehensive perinatal care programs for pregnant women and children. New growth in CHCs in the 1990s has generated new interest in these community-owned corporations, and a number of new center applications have been generated during the past 2 years for additional activities.

The federal government has initiated two new grants to assist communities with planning and coordination. The Health Care Financing Administration's Rural Hospital Transition Grant Program recently has assisted 14 Appalachian hospitals in planning and implementing activities to strengthen their financial bases and diversify their services.

New services have included health professionals recruitment, development of outpatient services, and planning for rural health care networks. The Office of Rural Health Policy's Rural Health Outreach Program has provided 11 grants to Appalachian coalitions of health and human service organizations to demonstrate the effectiveness of working together to address issues such as emergency services; case management for the disabled, the elderly, pregnant women, and children; and access to primary care services (Office of Rural Health Policy 1991).

Many of these planning efforts demonstrate the complexity of today's health care system. The development of a new service, such as mammography, requires at least four components. First, access to capital for the purchase of mammography equipment is required, which rural hospitals, because of their lower bottom-line profits, sometimes cannot afford. Second, some source of reimbursement for a patient's use of equipment is necessary. Fortunately, medicare and now medicaid in most states will pay hospitals a fixed amount on behalf of their patients. Considerations include whether employer-based health insurance policies will reimburse for tests and whether those who are uninsured or must pay providers themselves through deductible policies will use the service. Third, patients must want to use the service; therefore, hospitals must promote community health education, and local physicians must provide patient education about breast cancer risks and how the service will help detect cancer. And finally, physicians must be available, trained, and willing to read and interpret the mammograms and treat those patients diagnosed with cancer. The development of any new service is complex and requires a great deal of interprovider cooperation, financial support, and community demand.

A review of federal efforts also must include those of the Appalachian Regional Commission, an organization that looks at the health care issue from a regional investment perspective. It has been instrumental in making grant dollars available for more than the categorical program efforts described above. Since 1965, ARC has invested $106,902,000 in health facilities throughout the region. Health projects totaling $441 million represent 20 percent of total ARC dollars expended in the 25-year period of operation (Appalachian Regional Commission 1991). With its broadly stated mission of regional development, ARC has made health care investments strategically to complement other child development, education, community development, and highway expenditures within Appalachia (Appalachian Regional Commission 1991).

A 1991 study of 463 previous ARC-sponsored primary health care projects, generally funded on a matching basis with state and other dollars, showed that 75 percent of the organizations funded still operated primary care services. ARC dollars have been creative funds, unfettered by the tight restrictions or long-term commitments usually proscribed by other federal grants. Although ARC's funding for health care has been greatly reduced in the past 10 years, ARC has been active in studying and documenting health care issues prevalent in the region. A 1988 study outlined alternative actions to strengthen fragile rural delivery systems in the region (Gianfrancesco 1988). ARC recently funded programs to help create multiple-employer insurance trusts, to study the application of telecommunications and use of fiber-optic networks to make health care more accessible in rural areas, to improve use of early prenatal care through public information and education, and to study the impact of lower prospective payment system reimbursement from medicare on rural Appalachian hospitals.

States also have been involved in health systems development and special financing for the underserved. As costs of medicaid programs continue to escalate and the problems

of the health care systems become more visible, states have begun to develop their own strategies. These plans often have been generated through collaboration of a number of interests that combine the insider's perspective—state Offices of Rural Health, state health departments, and medicaid agencies—with the outsider's advocacy—professional medical, nursing, and public health societies and statewide associations of primary care physicians, hospitals, and others.

Medicaid programs are a federal-state partnership designed to provide insurance for those with very low income. Medicaid reimburses hospitals, clinics, physicians, nursing homes, and other providers for services provided to eligible patients. Each state is given some degree of flexibility in program eligibility, services, and benefits design, and each state receives matching funds based on a per capita income formula. Established in the 1960s, medicaid opened the door to health care for many Americans for the first time. States in recent years have been driven into health care reform debates because of the rapid growth of their medicaid expenditures, a large portion of which pays for long-term nursing home care for the elderly. These high costs are the result of federal mandates for expansions of eligibility as well as inflation in national health care costs. Several states have initiated efforts to contain costs including case management and managed care programs (Medicaid Bureau 1992)—the most recent being major proposals in Maryland and Tennessee. This approach designates a primary care provider (e.g., a physician) to coordinate the care of the medicaid patient, assuring continuity of services but also reducing the patient's freedom of choice. A number of Appalachian states have approved modified versions of this scheme, but the rural nature of Appalachian counties limits the potential cost-savings impact of the program.

A second major focus of state actions generally has been at the behest of organized providers; their statewide professional associations and uninsured consumers have taken up the issue of indigent care and health care reform. A significant portion of health care consumers have been faced with a lack of financial access to care, and providers have had to shift costs to absorb losses resulting from services to these patients. Crisis points were reached by states in the late 1980s, and a variety of innovative strategies have been developed paralleling states' long- and short-range efforts to address shortages of health professionals. Some approaches have included insurance market reform for small employers, reinstatement of the statewide certificate of public need review for capital projects, expansion of medicaid programs for specific high-risk groups (e.g., children), tort reform, and malpractice insurance coverage for obstetrical providers and others (Center for Policy Research 1992).

The private sector also has made efforts to develop and maintain systems. As is true across the country, much of the health care available in Appalachia has been organized through the private sector: private physicians' and dentists' offices, local community hospitals, and pharmacies. Public efforts of local health departments have supplemented this private provider system. Recently, with the move toward hospital mergers, alliances, and diversification, a greater amount of care is provided through organized systems such as multispecialty provider groups, hospital-owned practices and their support services (e.g., home health, nursing homes), and networks of providers organized by insurance companies.

The sense of community commitment to improving health can be seen clearly in the innovative evolution of one of America's largest employee health plans, the United Mine Workers of America Welfare and Retirement Fund (Derickson 1989). The mine workers represented by UMWA have had comprehensive medical coverage since 1950, and

the union initially operated its own chain of hospitals and a system of clinics and recruited providers. Comprehensive medical coverage has been financed through employee contributions and support negotiated through labor-management contracts. It has provided coverage for miners, their families, and retirees and has been the backbone of medical care in the coal counties of central Appalachia for decades. Negotiations for continued support of the growing costs of coverage have led to a number of bitter contract disputes. Efforts to document the effect of the termination of health care benefits on access and health status during a recent strike (Demers et al. 1990) demonstrated the interdependence of local health systems on their local economies.

Availability of Health Professionals

The second critical factor of health services is the availability of health professionals. The current political debate about health care reform, at both the national and state levels, is being driven by two major issues: cost-containment and access to care. Health care costs are best contained by preventing illnesses that result in costly hospital stays; access is best achieved when patients are able to see care providers early. Both are related to primary care, the backbone of any community health system.

The source of "first contact" care is primary care providers such as family and general practitioners, pediatricians for children, general internists for adults, and sometimes obstetrician/gynecologists for women. In many Appalachian counties, nonphysician providers (e.g., nurse practitioners, physician assistants, certified nurse midwives) are becoming more evident. Regardless, the general availability of providers in Appalachian counties is inadequate, as shown in Table 3. Health Professional Shortage Areas (HPSAs) are formally designated by the federal government as counties or parts of counties in which the ratio of primary care physicians to population is greater than 1 physician for every 3,500 residents (or 1 for 3,000 in areas with special needs like high rates of infant mortality or poverty). Table 4 compares the 1981 designated areas with those of 1991. In 1981, all or part of almost three-quarters of Appalachian counties contained shortage areas. By 1991, two-thirds remained designated, indicating that only one-third of all counties now have a sufficient number of health professionals to meet their needs.

The problems have not gone unrecognized. The federal government has sponsored intensive health professionals distribution programs such as the National Health Service Corps (NHSC) to target scholarships to medical and other health professional students who would serve in shortage areas (Rodos and Peterson 1990); the 1981-91 comparative data for Health Professional Shortage Areas do demonstrate some change. Forty-two percent of the Appalachian counties improved in their shortage area status. In fact, 67 counties improved to the point of becoming de-designated, therefore no longer requiring special federal recruitment assistance. Leading the achievement of de-designation were states with active support for work force distribution initiatives—namely, North Carolina and Pennsylvania, where 48 percent and 20 percent, respectively, of the areas achieved new de-designation.

Table 5 displays the massive efforts of NHSC to alleviate shortages during the 10-year period of 1983 to 1992. The services of health professionals located in Appalachian counties have been critical in reducing physician-to-population ratios as well as replacing the aging cadre of general practitioners. NHSC resources also have assisted organizations such as community groups and rural hospitals to develop newer, sustainable systems of care. Overall, 1,065 professionals were matched to Appalachian counties from 1983 to 1993, with 90 percent of these matched to rural counties.

The declining match number in the later

TABLE 3

Changes in Health Professional Shortage Areas (HPSAs) in Appalachian Counties: 1981-1991

Appalachian Part	Appalachian Population*	Number of HPSA Counties					
		Full 1981	Full 1991	Part 1981	Part 1991	None 1981	None 1991
Alabama	2,509,850	24	17	7	9	4	9
Georgia	1,508,030	14	15	1	3	20	17
Kentucky	1,045,357	23	20	8	9	18	20
Maryland	224,477	0	0	2	2	1	1
Mississippi	495,689	15	11	1	0	4	9
New York	1,039,507	2	0	9	12	3	2
North Carolina	1,306,682	15	3	6	4	8	22
Ohio	1,372,803	16	9	3	12	10	8
Pennsylvania	6,021,618	5	0	40	33	7	19
South Carolina	1,405,505	1	0	2	2	3	4
Tennessee	1,816,510	25	27	2	6	23	17
Virginia	476,803	8	5	4	4	9	12
West Virginia	1,550,762	25	16	21	27	8	12
Total	20,773,593	173	123	107	123	118	152

*One county was added after these figures were compiled.

Source: *Federal Register* 1981, 1991.

years after 1987 parallels the reduction of NHSC resources in the federal budget. Alarm in Congress about continuing shortages brought about major changes in the reauthorizing legislation for the National Health Service Corps Amendments Act of 1988. The law created a loan repayment program, a new mechanism allowing health professionals to practice in shortage areas in return for a federal contribution (and later through a state matching program) toward repaying their health professions education loans. Since 1988, 45 contracts were awarded to professionals such as physicians, nurse practitioners, and physician assistants who now practice in Appalachian counties.

Another major source of physicians has been the region's continuous recruitment and employment of foreign medical graduates. This program has become more formalized as part of the Revised J-1 Visa Waiver Program sponsored by the Appalachian Regional Commission. In the past 2 years, more than 200 physicians who have trained in the United States have been approved for employment and practice in the Appalachian region.

TABLE 4

Comparisons between 1981 and 1991 designated Health Professionals Shortage Areas

Appalachian Part	Worsened	Improved	Stayed Same	Redefined	Total	Totally Deleted	Percent Deleted
Alabama	6	18	7	4	35	7	20
Georgia	10	11	14	0	35	3	9
Kentucky	9	18	19	3	49	6	12
Maryland	0	2	1	0	3	0	0
Mississippi	4	12	4	0	20	7	35
New York	4	5	5	0	14	2	13
North Carolina	2	18	8	1	29	15	52
Ohio	6	13	8	2	29	2	7
Pennsylvania	7	31	7	7	52	11	20
South Carolina	1	3	2	0	6	2	33
Tennessee	12	8	30	0	50	1	2
Virginia	2	8	11	0	21	3	16
West Virginia	11	26	14	4	55	8	15
Total	74	173	130	21	398*	67	17

*One county was added after these figures were compiled.

Source: *Federal Register* 1981, 1991

Their time commitments are limited, and they are sponsored, in many cases by rural hospitals, to practice primary care in underserved parts of the region.

Despite these special efforts to place health professionals, shortages still exist. Sixty-five percent of Appalachian counties still qualify wholly (123 counties) or partially (124 counties) as shortage areas as noted in Figure 1. Twenty percent of the Appalachian counties suffered worsened shortages over the 10-year study. As another indicator of the problem, the ratio of physicians in patient care in rural counties was 43 percent higher than in nonrural counties in Appalachia (U.S. Department of Health and Human Services 1992).

The issue of availability of health care finally has been understood in the context of a general maldistribution and wrong mix of primary care and specialty providers being trained by health professions schools. Thus, several additional efforts are under way to help communities with shortages. New federal and state government cooperative agreements funded by the Public Health Service have spurred the identification of long-term strategies and investments.

One major strategy is the awarding of special incentives to practice in shortage areas. A revitalization of financial resources for new NHSC programs began in 1989, using three strategies: student scholarships, loan repay-

TABLE 5

National Health Service Corps Program: Number of health professionals matched to Appalachian counties, 1983-1992

Year	Physicians	Nurses	Dentists	Others	Total
1983	111	1	15	7	134
1984	162	1	19	12	194
1985	193	1	11	3	208
1986	180	1	8	1	190
1987	129	2	3	0	134
1988	58	0	0	3	61
1989	54	1	0	1	56
1990	23	2	0	1	26
1991	30	0	1	1	32

Source: National Health Service Corps 1992.

ment awards, and volunteer recruitment. The corps now once again places as many as 600 health care professionals in the neediest areas in the country each year. However, added emphasis has been focused on providing scholarships and loan repayment contracts to persons with minority and rural backgrounds. In addition to targeting physicians, the NHSC programs have made a set-aside for nurse practitioners, physician assistants, and certified nurse midwives. Finally, a new community scholarship program was instituted to allow local communities, states, and NHSC to share in the cost of educating local students in health professions schools and to have them return to their communities to work as repayment.

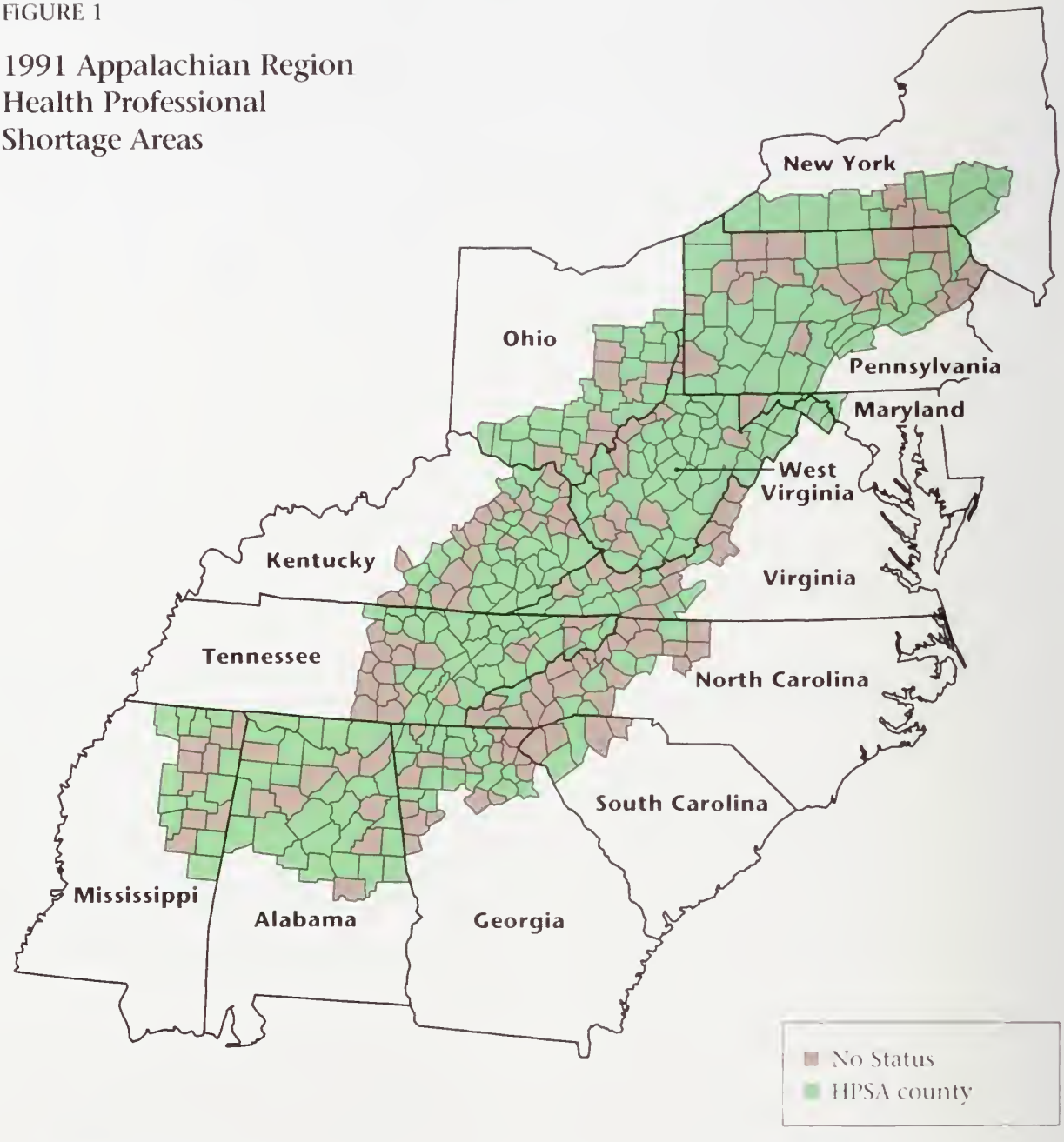
The federal government also has acted to redirect health professions training grants. Changes were authorized by amendments to Title VII and Title VIII Public Health Service programs for health professions schools in 1992 to give preference for grants, loans, and special project funds to those institutions that demonstrate success in placement of graduates in medically underserved areas. Priority also is given to schools whose students commit to pursuing careers in primary care, and new medical student loans are targeting those choosing primary care (U.S. Congress 1992). At the same time, a number of states are now beginning to instruct health professions schools, particularly medical schools, that their state budget allocations are contingent on the schools' doing a better job of training future physicians for primary care rather than specialty positions.

A number of Appalachian states provide financial incentives for providers to settle in communities with shortages. A few Appalachian states have recognized the importance of enticing not only physicians but also nurses and other allied health personnel through these strategies (American Hospital Association 1992).

Some strategies employed have included state scholarships for health professionals who were willing to commit to practice for many years in shortage areas of Appalachian states. Alabama, Georgia, and Virginia have initiated these programs. Spurred by the availability of federal matching funds through NHSC, many

FIGURE 1

1991 Appalachian Region Health Professional Shortage Areas



Source: Federal Register 1991.

states now offer loan repayment or forgiveness of health professionals' school debts. Eleven Appalachian states have these programs, with the amount of forgiveness ranging from $5,000 to $25,000 per year. New York and Tennessee also have established practice start-up grant programs to help new practitioners purchase equipment in underserved areas.

The second major strategy has included comprehensive long-term approaches to provider recruitment and retention. A greater understanding of the dynamics of attracting more health personnel into underserved Appalachian areas is resulting in new programs. They are based on an understanding of the need for a more comprehensive and long-term approach to recruiting from, exposing to, training in, and returning graduates to prac-

tice opportunities in underserved areas (Politzer et al. 1991). This continuum of contact is based on research and experiences of other geographic areas and cultural and ethnic minorities in providing for their long-term health care needs. For example, the Professional Education Preparation Program of the University of Kentucky and the University of Louisville, the Biomedical Science Preparation Program of the University of Alabama at Birmingham, and the Medical Applications of Science in Health Program at East Tennessee State University are directed toward interesting Appalachian high school and undergraduate college students in health careers (Straub and Wright 1992). Many Appalachian schools also support health career opportunities programs to interest Appalachian students in health careers. In addition, differential admissions policies have been established to promote selection of students from rural areas. These attempts have increased selection of primary care training and careers in rural areas (Rabinowitz 1988).

Expansion of student training experiences in rural Appalachian communities have been integrated into more curricula for health professions students. Two rationales support this strategy. Exposure of students to rural communities during training can sometimes spark long-term career interests in those or like settings. Likewise, these programs promote rural professionals as role models for students, unlike those normally encountered inside health professions training institutions. The special program sponsored at Marshall University in West Virginia is particularly effective in this regard. Support has been provided through NHSC scholarships to 104 medical students who received a part of their training in Appalachian counties.

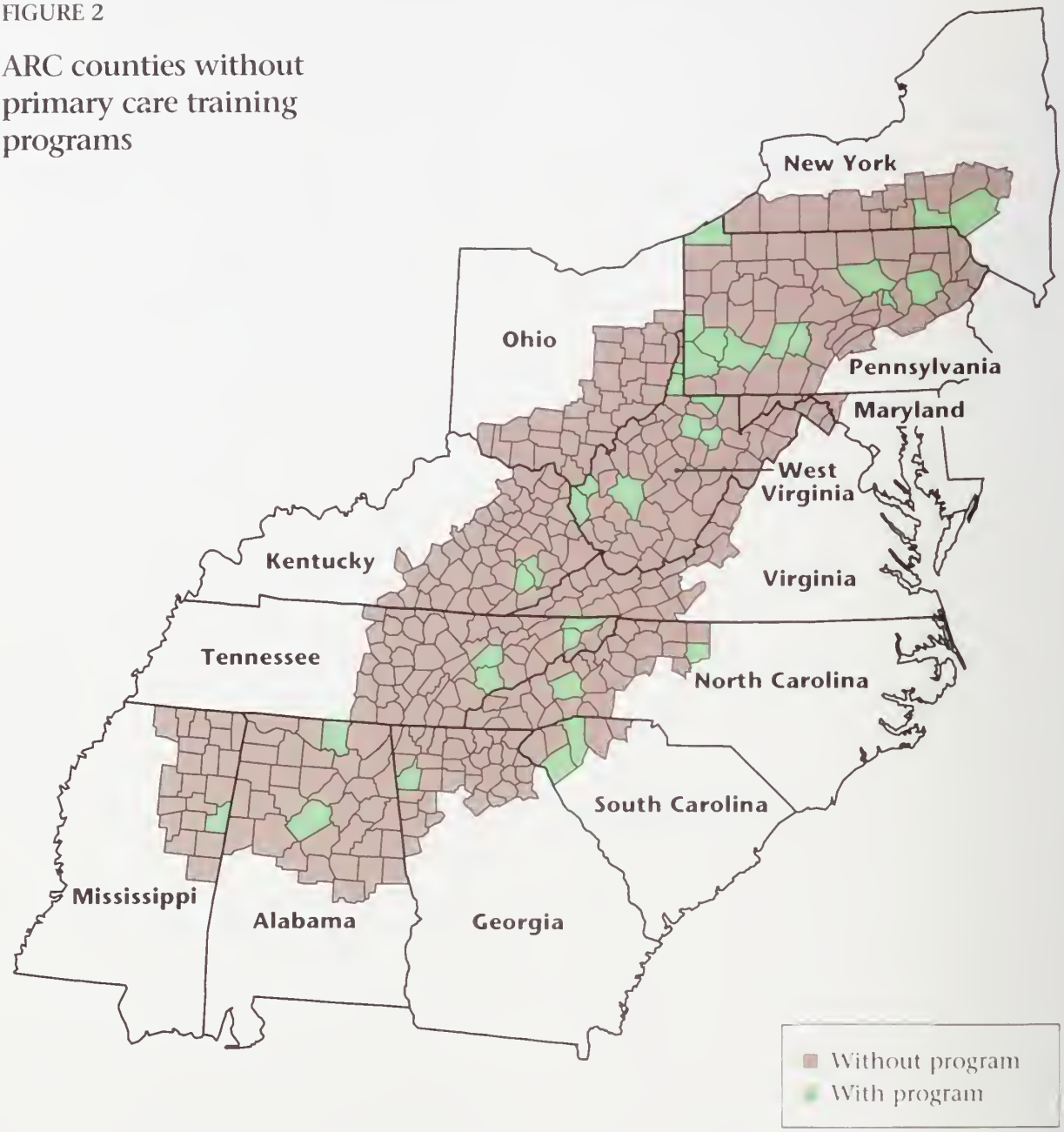
A number of states adopted the area health education center (AHEC) model in the early 1970s as a mechanism for providing training. This program, funded through medical schools, encourages training of health personnel in primary care and emphasizes the relationship between educational experiences and health care delivery. Nearly all the Appalachian states have a history of working AHEC programs, with North Carolina and South Carolina serving as long-term national models. The Mountain AHEC Program in Asheville, North Carolina, and the Southeast Area Health Education Center in Hazard, Kentucky, are outstanding sites where students from health professions programs located outside the region receive training in rural hospitals and community practices in Appalachia. AHECs have broad educational responsibilities to include all types of health professionals including medical, nursing, dental, allied health, and public health students in noncampus experiences. Many AHECs seek rural health care providers willing to act as preceptors for students as part of their regular curriculum of study. A recent study demonstrated that nonmetropolitan counties with AHECs have experienced greater growth in their supply of primary care physicians between 1975 and 1985 than have counties without AHECs (U.S. Congress, Office of Technology Assessment 1990).

Similarly, the new Community Partnership Program initiated by the Kellogg Foundation in 1991 at East Tennessee State University and a consortium of West Virginia universities use rural training sites linked with university resources to develop long-term interdisciplinary training experiences in rural communities for their students. West Virginia recently expanded its program by adding funding for additional training sites over a 5-year period beginning in 1993.

Many of the efforts described above focus on undergraduate health professions students such as medical students and nursing students. Influencing the next level of health professions education, such as residency programs and nurse practitioner training, through graduate-level programs to develop and operate in Appalachian communities has

FIGURE 2

ARC counties without primary care training programs



Source: HRSA Resource File 1991.

been somewhat successful. Figure 2 indicates the location of programs for family physicians, nurse practitioners, and physician assistants. The location of these programs is important for two reasons. First, many health professionals such as nurses seeking further advanced training must find programs within a reasonable distance from their homes. Second, many professionals have a tendency to settle within the area where they receive their advanced training.

For physicians, there are residency training programs in family practice sponsored by teaching hospitals in only 31 of Appalachia's 399 counties, almost all of which are in metropolitan areas. Limits on expansion of this strategy are primarily the result of accreditation and financing issues. However, many

programs have begun to place residents in smaller towns for month-long rotations, providing a good opportunity to experience rural life and practice.

Greater investment in the training and promotion of nurse practitioners, physician assistants, and certified nurse midwives is taking place in Appalachian counties. The employment of nonphysician providers in rural Appalachian communities has a rich history. Training programs were established for nurse practitioners and physician assistants in the 1960s. The training and use of certified nurse midwives in the United States was initiated in Appalachia through the Frontier Nursing Service in rural Kentucky in 1925. Many rural communities have found educating local residents through these programs and recruiting them back to their communities to be less difficult than securing physician services. Many physicians have coupled their services with nonphysician providers, forming health care teams to extend the availability of services. Nationally, 32 percent of nurse practitioners and 30 percent of physician assistants practice in rural communities, compared with 13 percent of physicians.

However, debate continues on a state-by-state basis concerning the definition of practice and reimbursement for the services of nurse practitioners and physician assistants. Changes in various state regulations regarding these professionals have been slow but constant. The scope of practice has improved in the past decade, including statutory authority for these professionals to prescribe drugs in 9 of 13 Appalachian states and statutes or regulations for certified nurse midwives in 11 of 13 states (Weissert and Knott 1992). Reimbursement policies for services remains another issue of concern. The 1978 Rural Health Clinics Act first allowed the services of nurse practitioners, physician assistants, and certified nurse midwives to be reimbursed for medicare and medicaid patients. Since that time, medicare has expanded its payment policies. Individual states determine state medicaid reimbursement policies, but most Appalachian states do provide some level of direct reimbursement.

Summary

The health care system in Appalachia suffers from some of the same deficiencies as rural health care across the country: shortages of providers, underfinanced services, and systems of health care in transition. Appalachian health care benefits from two strengths that have buoyed it over the decades. First, a sense of individualism and personalism has attracted providers like the "old country docs" and public health nurses to Appalachian counties. Second, a strong sense of community—taking care of everyone regardless of rank or status—permeates and supports efforts such as local hospitals, community clinics, and union health plans. The blend of these ethics has been battered by the outside forces of specialization of health care providers, inequitable health care financing for rural areas, and deterioration of smaller systems of delivery because of financial pressures.

Even if all availability factors were addressed and all Appalachian counties had sufficient numbers of health personnel and adequate financing of health care systems that supported a true range of health services, many residents would continue to suffer from a number of barriers to access. The mountainous geography of the region presents an ongoing travel challenge with comparatively little public transportation available for patients. For low- and moderate-income working families, access to health services beyond the traditional 9 a.m. to 5 p.m. availability is severely limited. It enforces a discontinuity of services, requiring the trade-off of lost wages or "urgent centers" and hospital emergency room care. Perhaps the most serious barrier to proper utilization of services, even when accessibility is ensured, is the lack of knowledge on the part of too many consumers regarding the need

CHAPTER 4
Action Steps

1. Assess the availability and accessibility of local health system resources and programs to address cancer prevention, screening, early detection, treatment, and aftercare needs.

2. Use existing health care facilities as sites for health promotion programs.

3. Implement initiatives to attract screening and prevention programs and services to your community.

4. Involve local residents of the lay and professional communities in outreach initiatives.

5. Evaluate current health personnel needs in your local area and incentive programs to recruit more physicians, nurses, and other allied health professionals to the region.

6. Conduct a community assessment of local medically underserved groups, and identify and surmount obstacles to their access and use of health resources.

for preventive health services. This problem promotes underutilization, an acknowledged issue even when preventive health services are made accessible at little or no cost, such as in many managed health care plans.

More health care decision making and resource allocation, at least at the policy level, will take place at national and state levels as the struggle continues to ensure access to care while containing costs. Juxtaposing this movement with the traditional Appalachian strengths of locality orientation will become and remain the challenge of the 1990s.

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CHAPTER 5

Lessons From Change Efforts in Appalachia

Stephen L. Fisher

Introduction

Contrary to popular images of Appalachians as passive victims, there exists throughout the Appalachian Mountains a tradition of individual and organized efforts to establish community services and preserve community values. This chapter describes the variety and extent of local and regional efforts for change in Appalachia since 1960, examines the lessons to be learned from these efforts, and discusses the relevance of these lessons to the Appalachia Leadership Initiative on Cancer (ALIC).[1] In particular, this chapter stresses the importance for ALIC to build on this tradition of grassroots-organized efforts and to overcome a number of obstacles to doing so.

The Politics of Change in Appalachia Prior to 1960

The Appalachian region has never lacked politics of change and alternative development. But what stands out in the literature describing life in Appalachia before 1960 is not the extent of change efforts but rather the obstacles to change, the conditions leading to quiescence (Eller 1982; Gaventa 1980). The industrialization of Appalachia was characterized by single-industry economies; the control of land and resources by large absentee companies; high levels of poverty and unemployment; the frequent use of red-baiting, intimidation, and physical force to squelch dissent; political corruption; and a highly stratified and oppressive class system. Collective struggles for change were further undermined by cultural traditions that stressed individualism, nurtured racial prejudice, and dictated passivity and acquiescence for women. Other factors contributed to this opposition of organized efforts in Appalachia. These included the strength of capitalist ideology, the lack of strong local organizations, high illiteracy rates, and poor transportation and communication systems.

During this period, an array of resistance to the starkest political and economic oppression in American society could be found throughout Appalachia. In recent years, anthropologists and social and feminist historians have taught us that when faced with such repressive conditions, people find ways to resist. This was certainly true in Appalachia. The organized efforts of workers in the coal, textile, and steel industries to improve their working and living conditions are well documented. However, in other parts of the Appalachian Mountains, responses to these conditions often assumed forms far less visible than picket lines and organized movements and included individual acts such as gossip, backtalk, holding on to one's dialect, refusal to cooperate with outside authority figures, and migration. This type of protest is part of what Scott (1990, pp. 4-5) refers to as the "hidden transcript" of the oppressed.

Increasingly, Appalachian scholars are coming to recognize the existence and importance of less visible and less heralded protest in

Appalachia's history and to understand that it has occurred most frequently in struggles to preserve traditional values and ways of life against the forces of modernization. For example, Lewis and colleagues (1978) describe the various ways in which mountain families and churches became defensive and inward to protect their members from some of the harmful impacts of industrialization and the actions of outside change agents. Blee and Billings

(1986) reinterpret early ethnographic studies of the region to show that work attitudes and other practices previously viewed as traits of a culture of poverty could better be understood as forms of resistance to the capitalist separation of work and control. Waller (1988) argues that the legendary Hatfield-McCoy feud can be seen as a battle between local defenders of community autonomy and outside industrial interests. Chapter 1 of this volume describes the cultural basis in Waller's account as well. These and similar studies broaden our understanding of the nature and extent of resistance by rural working-class and poor people in Appalachia prior to 1960.

Community Organizing in Appalachia Since 1960

Many obstacles that made collective struggles so difficult throughout Appalachia's history are still present today, and individual protests continue on a number of fronts. Nonetheless, new conditions after 1960 paved the way for organized change efforts in a variety of forms and settings in Appalachia. The civil rights movement helped legitimize the notion of dissent in general and the strategy of nonviolent civil disobedience in particular throughout the region and the nation. The environmental and women's movements offered models and resources for local groups in the mountains. Moreover, these movements provided the impetus for national legislation that created opportunities for local organizations fighting to save their land and communities from environmental destruction or working to create alternative economic opportunities for women. The antiwar and student movements called into question the notions of "progress," "modernization," and "national interest" that had been used for so long to justify the destruction of traditional ways of life in Appalachia.

The "War on Poverty" spawned the Appalachian Volunteers and community action agencies throughout the mountains. Although these programs had many weaknesses, they did bring young organizers into the region and provided opportunities for local leadership development. Mainstream churches, reflecting a new social consciousness, sent to Appalachia clergy and other church workers who were committed to working for social and economic justice. The construction of more and better roads, the availability of video recording equipment, the establishment of open meeting and record laws, and increased church and foundation funding of Appalachian citizen groups also contributed to local organizing efforts.

These and other factors led to an outburst of grassroots community organizing across Appalachia in the late 1960s and early 1970s. Local residents fought to prevent the destruction of their land and homes by strip miners, dam and highway builders, the U.S. Forest Service, toxic waste dumpers, and recreation and second-home developers. People organized to secure welfare benefits, to enact tax reform, to build rural community centers and health clinics, to fight for better schools for their children, and to establish programs in literacy and child care. Community groups pursued a wide variety of alternative economic development strategies that resulted in agricultural and craft cooperatives, worker-owned factories, and new job opportunities for women. Efforts to preserve and celebrate local culture flourished in the mountains as people began to develop a consciousness of and pride in being Appalachian.

In the 1990s, people across Appalachia are still fighting back, often around similar issues.[2] The battle over strip mining continues as local groups challenge the Office of Surface Mining's failure to enforce the federal strip mining law and join with other groups to lobby Washington for better water protection laws. Communities throughout rural Appalachia struggle to prevent their landfills from becoming the dumping ground for the nation's trash, sludge, and toxic waste. The

Yellow Creek Concerned Citizens and the Dayhoit Concerned Citizens in east Kentucky, the Dead Pigeon River Council and the Oak Ridge Environmental Peace Alliance in east Tennessee, and Concern About Water Loss Through Mining in western Pennsylvania are just a few of the groups across the region fighting the poisoning of their land, air, and water. The Tri-State Environmental Coalition organizes around industrial pollution where Ohio, Kentucky, and West Virginia meet. The Western North Carolina Alliance battles for an environmentally sound highway construction policy and against many of the timber policies of the U.S. Forest Service. The Ivanhoe Civic League and the Dungannon Development Commission in southwest Virginia and the Appalachian Center for Economic Networks in Athens, Ohio, pursue innovative grassroots plans for alternative economic development. The Mountain Women's Exchange and the Appalachian Women's Guild in east Tennessee and Women & Employment in West Virginia work to improve the economic position of women in the region.

In sum, since the 1960s, hundreds of new citizen groups have been organized throughout Appalachia. Most arose in response to a particular issue. These single-issue groups have worked together from time to time, helped create local leadership, and won important victories. However, because they have focused on a single issue, many of these groups have been short-lived, disappearing once their issue has been resolved (Bingman 1993). Thus, one of the most exciting and hopeful developments in community organizing in Appalachia in recent years has been the establishment and success of thriving and influential multi-issue, membership-driven organizations.

Save Our Cumberland Mountains, organized in 1972 to fight strip mining in a five-county area in the northern coalfields of Tennessee, changed from a single-issue, staff-run group to a multi-issue, grassroots organization able to exercise power and influence at the state and national levels. Kentuckians For The Commonwealth, started in mid-1981 by a small group of eastern Kentucky residents who wanted to address community problems that crossed county lines, has grown into a statewide, multi-issue, social justice organization of more than 2,300 members in 90 counties. The Community Farm Alliance was transformed from a handful of people who were replicating the mistakes of the national farm movement of the 1980s to a growing and successful membership-based organization with more than a dozen chapters across Kentucky.

These organizations stress the significance of local indigenous leadership recruitment and training, shared and long-term consciousness-raising, development of internal democratic social relations, ideological patience, and willingness to connect with people as they are. Their success illustrates the importance of using county chapters to build statewide organizations and of connecting local issues to state, national, and global patterns and concerns.

Labor Organizing in Appalachia Since 1960

The 1960s and 1970s were a time of widespread and intense labor activity throughout the Appalachian region.[3] Women's organizations arose to fight for women's employment rights in nontraditional job areas such as coal mining, highway jobs, and the building trades (Weiss 1993). The Amalgamated Clothing and Textile Workers Union (ACTWU) conducted a successful nationwide boycott of J.P. Stevens, which, at the time, was the second largest textile company in the country. Textile workers organized the Carolina Brown Lung Association to clean up their workplaces and to obtain compensation for those afflicted with byssinosis, a lung disease caused by inhalation of cotton dust. During this period, the Appalachian coalfields experienced one of the most militant rank-and-file mobilizations

in the postwar labor movement. Union miners, pensioners, and their spouses and widows organized to get black lung compensation and tougher mine health and safety laws, to throw out a corrupt and despotic union president, and to democratize their union, the United Mine Workers of America (UMWA).

Nonetheless, the 1980s were disastrous for organized labor in Appalachia and throughout the United States. Currently, less than 17 percent of the American work force is unionized, a smaller percentage than a half-century ago. UMWA membership fell from 160,000 in 1978 to less than 70,000 today. During the same period, the United Steelworkers of America (USWA) lost 58 percent of its members. Along with a decrease in membership has come a loss of labor rights in the workplace, deteriorating working conditions, a decline in bargaining power, and, for many workers, a drop in real wages.

But workers in Appalachia fought back. The employees of Weirton Steel Company in the small town of Weirton, West Virginia, responded to the threatened closure of their plant by organizing an employee stock ownership plan that eventually enabled them to become the nation's largest wholly employee-owned company. Steelworkers from western Pennsylvania, northern West Virginia, and eastern Ohio formed the Tri-State Conference on Steel to fight for job retention and renewal (McCollester and Stout 1990). In 1992, a well-orchestrated campaign by USWA defeated an effort by billionaire commodities trader Marc Rich's global corporation to destroy the union at the Ravenswood Aluminum Corporation in West Virginia.

ACTWU began to have success in organizing related industries, such as seat covers and tires. For example, in 1988, auto seat cover workers in a plant near Knoxville, Tennessee, voted to join ACTWU, as did Irwin Automotive workers in Dandridge, Tennessee, in 1990. The United Auto Workers (UAW) recently won victories at two small electrical motor suppliers in Hendersonville, Tennessee, and at an equipment manufacturer in La Vergne, Tennessee (Spears 1990). In 1989, temporary workers in Morristown, Tennessee, organized Citizens Against Temporary Services to push for legislation that would limit temporary assignments and force employers to give long-term employees regular pay and benefits. Retired and disabled Appalachian coal miners in the Black Lung Association, southern textile workers in the Brown Lung Association, and asbestos workers in the White Lung Association formed the Breath of Life Coalition to fight for a federal program that challenges many of the prevailing assumptions and practices regarding compensation and occupational health issues (Judkins 1993). UMWA launched strikes against the A.T. Massey Coal Group in 1984-85 and the Pittston Coal Company in 1989-90 in an effort to retain adequate health care, pensions, and job security for its members.

Workers and union officials in Appalachia and across the nation are increasingly aware of the need to adopt new tactics and strategies to confront corporate owners in an international economy. In some of the struggles mentioned above, ACTWU, USWA, and UMWA devised new and effective corporate campaigns to win concessions. These campaigns moved the battle away from the worksite to disrupt a company's relationship with stockholders or lending institutions by publicizing the company's poor record in financial, labor, environmental, or other policy areas. Unions recently have been pursuing a variety of electoral strategies, including running their own political candidates as Democrats or Independents. For example, during the Pittston strike, a local union official ran for the Virginia House of Delegates as a write-in candidate and won by a stunning two-to-one margin over a 20-year incumbent. Some unions, especially ACTWU and UAW, are rethinking traditional labor-management relations and are considering ways to restruc-

ture work systems and production policies to increase employee involvement in decision making in the workplace and in corporate boardrooms.

Union leaders are coming to recognize that the only effective response by workers to the increasing integration of the world economy is to coordinate their strategies both at home and abroad. Tens of thousands of workers from all over the country traveled to southwest Virginia to support union miners during the Pittston strike. ACTWU has worked diligently to build solidarity between clothing and textile workers in South Africa and North America. Australian miners and Japanese and Italian steelworkers took part in the organizing campaign against Pittston. The steelworkers at Ravenswood received crucial support from the Geneva-based International Metalworkers Federation and the Brussels-based International Federation of Chemical, Energy, and General Workers' Union. These union solidarity efforts provide a framework through which workers and their families in Appalachia can begin to understand the impact of national and global events and institutions on their lives and communities.

Efforts to Create an Appalachian Movement

Since the 1960s, activists have attempted to organize citizen and labor organizations in the Appalachian Mountains into a regionwide grassroots social movement. The most important attempts were by the Council of the Southern Mountains, the People's Appalachia Research Collective, the Congress for Appalachian Development, the Highlander Research and Education Center, and the Appalachian Alliance (Whisnant 1981; Clavel 1983; Glen 1993). These attempts to build a unified movement failed for a variety of reasons, but primarily because—unlike class, race, and gender—geographic region in the United States does not provide an adequate political and economic focus for social movements.

This failure to create a social movement in Appalachia similar to the civil rights or women's movements does not mean that change efforts in the region have occurred in isolation. Although many of these struggles have been local and concerned with a single issue, they often have been assisted by and associated with other groups and individuals within a loose alliance or network of Appalachian organizations. At times, the network has had a name; at other times, it has been little more than an informal chain of individuals and groups. Organizations and activists come and go, and financial support is rarely stable; but the network persists, and there may be no other like it in the United States (Horton 1989; Glen 1993). Key players in this network today include the Highlander Research and Education Center, an adult education center in eastern Tennessee that has served as a meeting place, training center, and catalyst for social action throughout Appalachia and the South; the Southern Empowerment Project, an organizer training program established and controlled by grassroots community groups; and the Appalachian Community Fund, a community-controlled foundation that provides seed money and small grants to groups in the Appalachian region.

As Horton (1989) points out, this loose, informal network

> *is the form that the Appalachian social movement has taken—slowly winning victories, working together, laying the groundwork, building or trying to build democratic organizations. Perhaps this is the way the movement will be built, piece by piece like a patchwork quilt until it comes together to rid the region of oppressive structures and practices, in turn becoming a piece of a much larger quilt that must be created to rid the nation of those same structures and practices (p. 370).*

Lessons Learned

This brief survey of organized change efforts in Appalachia should dispel the stereotypical notion of Appalachians as apathetic and dependent. Organizers of community-based efforts, such as ALIC projects, often will be able to draw on grassroots leaders and groups that have deep roots in the local community and broad experience in working to improve local conditions. However, to recruit these leaders, to tap into that experience, and to bring about substantive change, organizers of community-based efforts should consider the "lessons" that activists and academics have learned about the politics of change in Appalachia.

Successful change efforts in the Appalachian Mountains have centered more often around the concept of "community" than around the centralized workplace of the mine, mill, or factory. In addition, many of the popular struggles in the region have been fueled by historical memory and reliance on and defense of traditional values—a strong commitment to land, kin, and religious beliefs; an emphasis on self-rule and social equality; and patriotism. Indeed, the fact that so many of the protests in Appalachia have been the result of defensive behavior—action to prevent the destruction of a way of life and of a set of values that could be considered traditional or conservative—has led one observer to refer to Appalachians as "reactionary rebels" (Lewis 1987, p. 22).

Although it is important to understand that grassroots resistance in Appalachian history most frequently has occurred in single-issue battles to preserve traditional values and ways of life, it is also necessary to recognize that there are limits to community-based organizing strategies that focus on single issues and rely heavily on localism and traditional values and institutions.[4] Community historically has entailed exclusion as well as inclusion. Tradition and local values include racism, sexism, homophobia, and isolationism. In addition, although localism offers a number of advantages, few significant problems can be solved at the local level. Local resources have been depleted and local economies gutted by national and global market forces and the actions of the federal government and multinational corporations. Those organizing in Appalachia must find ways to clarify the connections that exist between local work and national and international institutions if local citizens are to understand the importance of national and international forces as determinants of what happens locally and to see themselves as actors at the national level.

Without attention to the larger questions of power in society, local community groups often are not prepared for the legal, political, and cultural forces that established powers bring against them. This results in a politics of gradualism—a strategy of adaptation and retrenchment—and a suspicion of outsiders and their programs. Furthermore, it does not create the conditions necessary for coalition work with potential allies such as health professionals, church workers, or environmentalists. Many local revolts throughout Appalachia turn out to be "flashes of independent anger" rather than sustained efforts at effective movement building precisely because they lack an analysis and understanding of power beyond the local level.

In sum, single-issue, defensive, localized work, which has characterized much of the organizing in Appalachia, can win occasional victories but alone cannot lead to substantive change at an individual or structural level. Tackling issues as complex as poverty, cancer, or inadequate health care requires ongoing, multi-issue, reflective, democratic organizations and the type of organizing being conducted by Save Our Cumberland Mountains, Kentuckians For The Commonwealth, and the Community Farm Alliance—the multi-issue, membership-run organizations described above. These groups pursue an organizing approach that is flexible, pragmatic, and

grounded in the past and present of members' lives. But unlike the narrow single-issue organizing of the past, these groups' primary concern is to empower their members for the long haul—to provide a schooling in politics and personal empowerment. They do so by offering a self-conscious leadership training program designed to develop democratic skills and build a sense of ownership and comm unity. These organizations provide the space where participants can begin to see the connection between their concerns and those of other exploited people, where members can come to confront issues of racism and sexism, and where people can start to envision new alternatives to the state of the world in which they live. As Connie White, past president of Save Our Cumberland Mountains, puts it, "We don't care just about winning issues; we care more about helping people get stronger. In the long run, that is how you win issues and make real changes" (Allen 1993, p. 96).

In the past, many organizers have arrived in Appalachia with pejorative, romanticized, or contrived notions of the cultural forces and values present in the Appalachian Mountains. Appalachian culture is "a web of both resistance and complicity" (Whisnant 1976, p. 46), and it is important for those organizing in the region to develop an understanding of the ways in which regional culture informs the construction of class consciousness, race and gender relations, regional identity, and community life.

Several points need to be emphasized in this regard. First, regional identity and cultural pride are not naturally part of community life. As Couto (Chapter 1, this volume) explains, regional identity is not a geographical or cultural given in Appalachia but must be understood as an outgrowth of political and social change. Similarly, local cultural traditions are selective and fluid in nature; they are "historically formed, situated, and altered by people interacting with each other and with social and economic forces" (Schwartz 1983, p. 78). These cultural traditions are at the heart of the community networks necessary to sustain people during protracted struggles and to enable them to foster change on their own terms. Nevertheless, cultural expression does not always arise spontaneously in struggles to challenge oppression and inequality. The seeds for such expression exist, but these seeds often must be deliberately cultivated and nourished by organizers and institutions that recognize the value of cultural forms to resistance efforts.

Second, neither class nor culture alone is a sufficient tool for understanding political action in Appalachia. Although shaped by economic concerns, classes are cultural configurations. Indeed, the United States is one of the few places where class and culture are thought of separately. Lived experience is different—our lives are a messy amalgam of identities out of which social relations are conducted (Scott 1985, p. 45). The difficult but crucial task is not to decide between culture and class, but to discover how class, race, and gender conflicts express themselves today in cultural and political formations in Appalachia.

In Appalachian research, some of the most important work in this regard is being done by Anglin (1990) and Maggard (1990). Using different approaches and studying protest in different locales and industries, both Anglin and Maggard probe the ways in which gender, kinship, and social class interact to specify women's political experience, action, and consciousness. They demonstrate convincingly how and why change efforts, to be successful, must be situated in a web of work, family, and community needs and histories. Other significant contributions include Yarrow's (1991) investigation of the ways in which Appalachian coal miners' gender consciousness affects their class consciousness, Couto's (1986) discussion of community-based approaches to environmental risks, and Billings' (1990) use of Antonio Gramsci's

approach to religion to explain activism and quiescence among textile workers and coal miners.

Third, racism is a major barrier to successful grassroots organizing and coalition building in Appalachia, as it is throughout the nation. Manning-Miller (1993) charges that many community organizations in Appalachia—although committed either explicitly or implicitly to combatting racism and to building a multiracial people's coalition for progressive social change—in practice pursue a process of organizing and struggle that fails to challenge the cultural conservatism and racism of their constituency. Manning-Miller urges organizers and activists to use all available media and organizational forms to confront people's racism and offers a number of valuable tactical measures and suggestions for developing a systematic program to confront racism in Appalachia.

Finally, to be successful over the long haul, those engaged in cultural, educational, and political work must search through the regional culture to locate its most humane, progressive, and transformative elements and then look for ways to link these transformative elements to a larger human agenda for change (Whisnant 1991).

Conclusion

What are some of the implications of the lessons of recent community-organized efforts in Appalachia for programs of community-based problemsolving such as ALIC's cancer prevention and health promotion programs? What challenges and opportunities do these lessons pose for project staff? What types of questions do they raise concerning organizing strategies and tactics?

Appalachians are not simply sitting passively, waiting for the project staff of institutionally based programs to empower them. Rather, cancer prevention and control programs will be occurring in the context of a long tradition of local community organizing. This tradition has at least two components: (1) people organizing to fight against efforts to change them, to move them, and to destroy their land or way of life and (2) people organizing to secure services to improve the quality of their lives. The latter element of the tradition is something that community-based coalitions might build on; the "fight" element is something they may find themselves up against.

People in rural Appalachia frequently have been used as guinea pigs in the past and are suspicious of outside authority figures coming into their communities with set agendas, victim-blaming assumptions and methodologies designed to change their behavior, and an unwillingness to address the structural causes of the region's most pressing problems. University-based programs, such as the ALIC projects, will appear to many residents, at least at first glance, as just another in a long line of efforts by outsiders to denigrate their culture and lifestyle. Health professionals involved with these programs may find indifference, if not outright opposition, to their health promotion attempts that focus on changing diet and behavior patterns. To combat this reluctance, staff members must clarify the ways in which their project is different from previous failed efforts by outside experts, including the medical profession, to change people's behaviors.

One way that community-based coalitions can demonstrate that their projects are different is for staff members to accept people the way they are. This involves an awareness that most people are concerned about safe and secure jobs that pay a decent wage, better social services, good education for their children, a safe living environment, and access to quality and affordable health care. For decades, people throughout the Appalachian region have been organizing to secure these benefits and to improve their quality of life. For example, Appalachians have organized welfare rights groups, challenged entrenched and politically powerful educational bureau-

cracies, and established community-controlled health clinics. It is this part of the tradition of resistance in Appalachia that programs such as ALIC could tap into because of their institutional base. However, if people are to be open to promoting a change in lifestyle and personal habits, they must know that the staff understands these structural problems and is willing to help address them.

This will not be an easy task. The history of community organizing in Appalachia teaches us that many local political and business officials, who undoubtedly will participate in community coalitions, will oppose efforts to link the coalitions' specific agendas to broader community concerns. Some local citizen groups, central to ALIC's success, may expect health professionals involved with these coalitions to help group members assess the possible health risks of local environmental threats. These professionals, without comprehensive studies and hard scientific data, may be hesitant to do so. It will be difficult to overcome low-income residents' well-founded distrust of outsiders in general and the medical profession in particular in such a situation. That distrust can lead to an assessment that ALIC is not effective in cancer prevention and control.

The most important step in securing trust in community-based coalition building from the outside is to enter a community with an open mind and an awareness that local people have something to teach "the experts." Outsiders need to be aware of community resources and what the community is doing for itself. They must understand and show appreciation for the indigenous customs, values, and knowledge that lie at the heart of the community networks that enable people to foster change on their own terms. This involves some form of cultural fieldwork; no single cultural approach will work in Appalachia because, as explained above, local cultural traditions are selective, historically formed, and fluid in nature.

It is, of course, crucial that the staffs of community-based coalitions, such as the ALIC projects, set agendas together with their primary constituency—rural, working-class, low-income Appalachians. This involves creating a structure that will enable them to listen to each other to determine what they need from each other as well as what they have to teach each other. The notions of constituency and structure lead to a series of questions, the answers to which could well determine the success or failure of community-based endeavors.

In terms of constituency, how do staff members of community-based coalitions propose to identify and use grassroots leaders? If staff members do their work well, they will not find docile people, but ones to whom they will have to prove the sincerity, usefulness, and seriousness of the project. A related question is: What relationship, if any, will programs such as ALIC have with labor unions and the wide variety of citizen groups in the Appalachian region? These organizations have strong ties with populations that are primary targets for cancer prevention and control programs and could serve as valuable allies in legitimizing ALIC's activities. However, the primary concerns of these groups are the political development of their members and organized efforts to change structural conditions that adversely affect their members and local residents. In what ways are community-based programs such as ALIC able or willing to convince these organizations that they share similar concerns?

How will ALIC coalitions within local communities be structured? The project staff will feel more at ease with social service professionals, business leaders, government officials, and middle-class volunteers. How will project leaders recruit consumers, patients, and working-class and low-income members? How will they deal with class issues and suspicions in the community coalitions and in the community at large? How will they involve local

minority groups, such as African Americans and Native Americans, in the project? How do they propose to give local people a sense of ownership of the coalitions?

Another important set of questions concerns the geographical unit that community-based programs should adopt. If, as argued above, the lack of an Appalachian identity makes a regionwide coalition impractical, what should be the focus of ALIC's four projects in the region—the county, local development districts, or the state? The most successful community organizing in Appalachia has been based on county and state coalitions. But ALIC projects cross state lines and include coal and noncoal counties. This concern points to the need for new organizing strategies that can build bridges across county and state lines.

ALIC project staff face an important choice in Appalachia. Will their projects primarily be another endeavor in Appalachia that views local people's behavior as a problem to be solved? Or are they to be projects for Appalachian people—projects that empower them by identifying and using local cultural resources and by helping them make the broader connections between cancer prevention and control and the need to change both individual behavior and systemic causes of cancer? ALIC projects choosing the first option will resemble the Appalachian single-issue groups discussed above; they are likely to have a limited and short-term impact. However, if ALIC projects choose the latter option and pursue an organizing approach that is flexible, democratic, pragmatic, and grounded in the past and present of the participants' lives, they will resemble the highly successful membership-run organizations such as Save Our Cumberland Mountains, Kentuckians For The Commonwealth, and the Community Farm Alliance (Allen 1993; Hamilton and Ryan 1993; Zuercher 1991). Adopting such a strategy would enable projects involving community-based coalitions to develop client-centered health centers for cancer where local residents feel a sense of ownership and community. This second option is by far the most difficult and challenging one, but it is the only one that offers the possibility of substantive change over the long haul.

Notes

1. This discussion draws heavily from Introduction and from Conclusion: New populist theory and the study of dissent in Appalachia, both written by S.L. Fisher. In: Fisher, S.L., ed. *Fighting Back in Appalachia: Traditions of Resistance and Change.* Philadelphia: Temple University Press, 1993.

2. *The Appalachian Reader: An Independent Citizens Quarterly* serves as the most important, regular, and up-to-date source of information on grassroots organizing in Appalachia. See also Fisher, S.L. Dissent in Appalachia: A bibliography. In: Fisher, S.L., ed. Fighting Back in Appalachia: Traditions of Resistance and Change. Philadelphia: Temple University Press, 1993, pp. 339-360.

3. For a discussion of sources on labor issues and struggles in Appalachia after 1960, see Fisher, S.L. Dissent in Appalachia: A bibliography. In: Fisher, S.L., ed. *Fighting Back in Appalachia: Traditions of Resistance and Change.* Philadelphia: Temple University Press, 1993, pp. 346-351.

4. The following discussion draws from a variety of sources that are part of a vigorous debate in community organizing circles during the past decade over what organizational instruments and strategies are best suited for building progressive citizen groups and political movements. These sources can be found in Fisher, S.L. Conclusion: New populist theory and the study of dissent in Appalachia. In: Fisher, S.L., ed. *Fighting Back in Appalachia: Traditions of Resistance and Change.* Philadelphia: Temple University Press, 1993, pp. 317-336.

CHAPTER 4

Action Steps

1. Build statewide and regionwide networks of local community-based coalitions. Use these networks to better connect local issues to state and national concerns.

2. Clarify the connection between local efforts and those of state and national institutions, and encourage local ALIC participants to see themselves as actors at not only the local but also the national level.

3. Draw on grassroots leadership and groups that have long histories in the local community and broad experience in working to improve local conditions.

4. Center health promotion efforts around the concept of "community" as defined by local people, and situate ALIC initiatives in the intricate network of work, family, and community needs and histories.

5. Use ALIC to create ongoing, multi-issue, reflective, and democratic coalitions that empower their members, offer leadership training, teach democratic skills, and foster a sense of ownership in community matters.

6. Address class, ethnic, and gender conflicts as obstacles to effective coalition processes and outreach activities.

7. Extrapolate the most humane, progressive, and transformative elements of a local area's culture, and link these elements to the local coalition's agenda for change.

8. Foster friendly and trusting relationships with people of the local area by involving them in every stage of program planning, development, and implementation.

9. Be sensitive to the needs, histories, and traditions of community residents, and avoid coming into communities with set agendas, victim-blaming assumptions, specific methodologies designed to enhance behavior, and a blind eye to the social, political, and economic causes of the region's problems.

10. Be aware of community resources and community efforts to improve the life of its people. Utilize the leaders and traditions of these efforts.

11. Create a working coalition structure that involves members of the target populations and enables coalition members to listen and learn from each other.

12. Develop programs that not only reach out to community residents but also empower local people.

13. Identify and use local cultural resources.

14. Help community members make the connection between cancer prevention and changing both individual behavior and systemic causes of cancer.

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SECTION II

Preparing the Soil

SECTION II

Preparing the Soil

The chapters in this section offer an overview of the context of community-based coalition efforts to improve health status and care. The chapters address national resources and lessons rather than those specific to Appalachia. Of course, these resources and lessons are related—as are all other elements of Appalachia—to national resources and events, as Section I made clear. Whereas Section I offered solid ground on which to stand in community-based coalition efforts in Appalachia, this section offers the tools and insights with which to work the soil for successful community-based coalition efforts in health interventions, specifically cancer prevention and control. Consequently, each chapter in this section provides information on some large area of interest to community-based coalition efforts to prevent and control cancer and relates that information to Appalachia.

Chapter 6, for example, describes the federal government's health promotion objectives related to cancer, which are presented in *Healthy People 2000* (U.S. Department of Health and Human Services 1991). These objectives for the nation represent the most ambitious effort yet to identify preventable aspects of illness, to measure risks, and to set objectives to reduce those risks by the year 2000. Chapter 6 is particularly useful to introduce readers to our knowledge about cancer, its causes, and several programs to address them. Chapter 7 explains that poverty lurks behind several risks for cancer. This chapter examines a wide range of studies to specify elements of socioeconomic status associated with cancer—for example, literacy and access to health care. It also provides recommendations for community-based health promotion efforts intended to serve low-income groups.

Chapters 8 and 9 provide information on coalitions. Chapter 8 provides a general view of community-based coalitions in a broad array of areas, such as neighborhood improvement and health. This chapter presents the lessons we have learned about the types of community-based coalitions, their formative processes, and their maintenance. Chapter 9 examines previous and current efforts of the National Cancer Institute (NCI) to conduct coalition activities for cancer prevention and control. This chapter provides an institutional rationale for coalition work that complements the community rationale presented in Chapter 8. The four broad coalition efforts described in Chapter 9 furnish community-based coalition health efforts resources on which to borrow and ideas to replicate. In research original to this volume, this chapter distills knowledge gained from the several coalition efforts of NCI. In addition, Chapter 9 offers information on resources within NCI that are helpful for any community-based coalition effort on cancer prevention and control.

Chapter 10 provides insight into recent organized efforts that combine and extend elements of the other chapters in this section. It describes the development, rationale, and functions of advocacy groups, with a focus on those organized around breast cancer. This chapter introduces powerful new players and their efforts to improve cancer prevention and control. It also describes one set of organized efforts by patients and activists to use and improve existing cancer resources and to develop new ones with more representation and participation of cancer victims. These efforts, which sometimes produce conflict, offer the prospect of greater collaboration between health professionals and informed, organized health care consumers for more effective client-based approaches in health promotion. In this development effort, Appalachia has many precursors, including the black lung movement and the development of community health centers.

Regardless of how much insight they provide, the chapters of Section II also make clear how much more there is to learn. The way in which the objectives and measures of *Healthy People 2000* apply to rural areas is not clear. For example, are the objectives reasonable for rural areas where availability of and access to health resources are limited? In addition, much of what we know about the relationship between socioeconomic status and cancer comes from studies of race and cancer. Those studies emphasize that cancer is related to poverty rather than race. Too few studies specify how poverty and cancer are related. This information is obviously important for coalitions, in areas with high poverty rates, to develop strategies related to the groups with highest risks for illness, including cancer.

Similarly, despite what we know about community coalitions and coalition efforts within NCI, each community-based coalition, such as those supported by the Appalachia Leadership Initiative on Cancer (ALIC), will have to wrestle with establishing an organization that represents all groups necessary for an effective program: those at risk and providers of services, critics and defenders of services and programs, locally elected officials and informal community leaders, and professionals and "creekwise" intellectuals.

In the last chapter of Section I, Fisher cautions that a gap may develop between the agenda of community-based coalition interventions, such as ALIC projects, and the agenda of the community leaders whom those interventions seek to involve. Fisher cites environmental risks as an example. Many of the current community-organized efforts in Appalachia are aimed at stopping solid waste and hazardous material dumps and incinerators in the region. Health professionals have not reached conclusions about the health risks that these measures represent. As if to illustrate Fisher's point, Chapter 6 points out the gap in information that exists about the relation of occupation and environment to cancer. Chapter 10 warns of some conflicts that may develop within coalitions between the patients and activists and the gatekeepers of the current health care system.

Thus, this section primarily addresses prospects of health interventions by community-based coalitions. Secondarily, however, it also discusses the problems associated with developing those prospects. The chapters in the section describe what we know and do not know about risks for cancer and coalition efforts to address them. Like the chapters of Section I, those in Section II offer information about the context within which the ALIC projects will work. This context includes work in related areas and models of coalitions that

have preceded ALIC. This work and these models provide practical experience that has prepared the ground on which ALIC works and resources on which ALIC projects can draw. Implicit in the discussions of the chapters in this section are the prospects of work and models of health promotion that develop, and improve, those that preceded ALIC.

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CHAPTER 6

Healthy People in Rural Areas by the Year 2000

Barry Portnoy

Introduction

The purpose of this chapter is to familiarize the reader with the U.S. Department of Health and Human Services' initiative *Healthy People 2000* (U.S. Department of Health and Human Services 1991). The initiative provides a framework and prioritization for health promotion and disease prevention efforts for federal, state, and local agencies. Included in this chapter are cancer-specific national health objectives and their scientific rationale, the existing data sources and gaps for monitoring progress toward the objectives, and selected National Cancer Institute (NCI) interventions that hold promise for effecting positive change. *Healthy People 2000* benefits state and local public health professionals by providing a blueprint for action. It also provides a list of comprehensive health objectives that can be used for program development and evaluation.

The Year 2000: A Cancer Profile of the American People

The 1979 *Surgeon General's Report on Health Promotion and Disease Prevention—Healthy People* targeted five broad national goals for 1990, one goal for each of the five major stages of life—infants (under 1 year), children (1 to 14 years), adolescents and young adults (15 to 24 years), adults (25 to 64 years), and elderly (65 years and older) (U.S. Department of Health, Education, and Welfare 1979). Similarly, *Healthy People 2000* uses the same age groups for specifying national objectives and monitoring change and is organized into three broad areas. The first goal is to increase the healthy lifespan of Americans.

The second goal is to reduce the health disparities among Americans, directed at improving death, disease, and disability rates for racial and ethnic populations and people with lower income levels compared with the total general population. Unfortunately, recent data show that African Americans bear a disproportionate burden of cancer, marked by increasing mortality rates for a number of cancer sites, including the larynx, oral cavity, pancreas, colorectal, prostate, and female breast. The Hispanic cancer experience also differs from that of the white population with higher rates of cervical, esophageal, gallbladder, and stomach cancers. The rate of incidence (or new cases of cancer usually expressed in rates per 100,000 population) in breast and lung cancers is increasing among Hispanics with diagnoses at later stages and resultant lower survival rates.

The third goal is to achieve access to preventive services for all Americans. Again, there are major disparities of access to preventive services between minority and underserved populations compared with the general population.

The average life expectancy at birth increased to 75 years in 1989, representing

a gain of 28 years since the beginning of the 20th century. Unfortunately, the life expectancy for African Americans has remained behind that for the total population and, as of 1989, was 69 years.

In 1994, an estimated 538,000 people will die of cancer—one of every five deaths in the United States (Boring et al. 1994). It is also estimated that 1,208,000 new cases of cancer will be diagnosed in 1994, a figure that does not include carcinoma in situ and squamous cell skin cancers estimated at 700,000 cases per year. Table 1 depicts the estimated new cancer cases and deaths for 1994 for the major cancer sites.

Cigarette smoking has been identified as the largest preventable risk factor related to mortality. It is estimated that more than 419,000 lives are lost each year, primarily from lung cancer, cardiovascular disease, and chronic obstructive lung disease linked to tobacco use. The American Cancer Society (ACS) estimated that in 1993 approximately 160,000 people would die of tobacco-related cancers. The smoking prevalence rate for adults in the United States age 18 years and older was 25 percent in 1991, which means that approximately 50 million Americans were regular users of cigarettes (Boring, et al. 1994). A major concern is that the percentage of women who smoke is about the same as it was 35 years ago, whereas the percentage of men who smoke has dropped. Alarmingly, the percentage of our children who smoke has not declined in the past decade despite major efforts by federal, state, and voluntary agencies. More than 3,000 teenagers become regular smokers each day in the United States (Boring et al. 1994).

Smoking is inversely related to educational level—42 percent of men and 32 percent of women who did not finish high school reported themselves as current smokers in 1990. This is in contrast to men and women who

TABLE 1

Estimated New Cancer Cases and Deaths for 1994
All Races, By Sex

Primary Site	Estimated New Cases			Estimated Deaths		
	Total	Males	Females	Total	Males	Females
All Sites	1,208,000	632,000	576,000	538,000	283,000	255,000
Oral Cavity and Pharynx	29,600	19,800	9,800	7,925	5,150	2,775
Lip	3,300	2,800	500	75	50	25
Tongue	6,000	3,800	2,200	1,750	1,100	650
Mouth	11,100	6,600	4,500	2,100	1,200	900
Pharynx	9,200	6,600	2,600	4,000	2,800	1,200
Digestive System	233,300	123,100	110,200	121,450	64,550	56,900
Esophagus	11,000	8,000	3,000	10,400	7,800	2,600
Stomach	24,000	15,000	9,000	14,000	8,400	5,600
Small Intestine	3,600	2,000	1,600	950	500	450
Colon	107,000	52,000	55,000	49,000	24,000	25,000
Rectum	42,000	23,000	19,000	7,000	3,800	3,200
Liver and Intrahepatic Bile Duct	16,100	8,800	7,300	13,200	7,200	6,000
Pancreas	27,000	13,000	14,000	25,900	12,400	13,500
Other Digestive	2,600	1,300	1,300	1,000	450	550
Respiratory System	189,000	112,800	76,200	158,200	96,900	60,300
Larynx	12,500	9,800	2,700	3,800	3,000	800
Lung and Bronchus	172,000	100,000	72,000	153,000	94,000	59,000
Other Respiratory	4,500	3,000	1,500	1,400	900	500
Bones and Joints	2,000	1,100	900	1,075	600	475
Soft Tissues	6,000	3,300	2,700	3,300	1,600	1,700
Melanomas of Skin	32,000	17,000	15,000	6,900	4,300	2,600
Breast	183,000	1,000	182,000	46,300	300	46,000
Genital Organs	283,400	208,100	75,300	63,725	38,525	25,200
Cervix Uteri	15,000		15,000	4,600		4,600
Corpus and Uterus, NOS	31,000		31,000	5,900		5,900
Ovary	24,000		24,000	13,600		13,600
Other Female Genital	5,300		5,300	1,1000		1,100
Prostate	200,000	200,000		38,000	38,000	
Testis	6,800	6,800		325	325	
Other Male Genital	1,300	1,300		200	200	

continued

TABLE 1 *(continued)*

Estimated New Cancer Cases and Deaths for 1994
All Races, By Sex

Primary Site	Estimated New Cases			Estimated Deaths		
	Total	Males	Females	Total	Males	Females
Urinary System	78,800	55,000	23,800	21,900	13,800	8,100
Urinary Bladder	52,200	38,000	13,200	9,900	6,500	3,400
Kidney and Other Urinary	27,600	17,000	10,600	11,300	6,800	4,500
Eye and Orbit	1,750	950	800	250	125	125
Brain and Other Nervous System	17,500	9,600	7,900	12,600	6,800	5,800
Endocrine Glands	14,450	4,150	10,300	1,725	750	975
Thyroid	13,000	3,400	9,600	1,025	400	625
Other Endocrine	1,450	750	700	700	350	350
Lymphomas & Myelomas	65,600	35,900	28,700	29,700	17,100	15,450
Hodgkin's Disease	7,900	4,400	3,500	1,550	900	650
Non-Hodgkin's Lymphoma	45,000	25,000	20,000	21,200	11,200	10,000
Multiple Myeloma	12,700	6,500	6,200	9,800	5,000	4,800
Leukemias	28,600	16,200	12,400	19,100	10,500	8,600
All Other Sites	43,000	24,000	19,000	41,000	21,000	20,000

Excludes basal and squamous cell skin and in situ carcinomas except urinary bladder. Incidence estimates are based on rates from the NCI SEER Program 1988-90.

Source: Boring CC, Squires TS, Tong T. 1993. With permission from J. B. Lippincott Company.

graduated from college, of whom about 15 percent and 14 percent, respectively, smoked in 1990. The Appalachian region, with a lower average educational level, exhibits higher smoking rates and corresponding increased risk of cancer and heart disease.

For breast cancer, an estimated 182,000 new cases will be diagnosed in women in 1994. Breast cancer is the second leading cancer site in women, having recently been surpassed by lung cancer. According to ACS, approximately 46,000 women will die of breast cancer in 1994 (Table 1). The early detection of breast cancer increases the chances of survival dramatically. Regular screening can reduce breast cancer deaths by an estimated 30 percent. Unfortunately, only 47 percent of women age 50 years and older have received a clinical breast examination and mammogram within the past 2 years.

The early detection of cervical cancer, as with breast cancer, can have a significant effect on the mortality rate. In fact, the Pap test has contributed to a 50-percent decline in cervical deaths since 1969. Currently, 93 percent of women age 18 and older report ever

having had a Pap test, and 83 percent report having had the test within the past 3 years.

Rural Population as a Special Population

The term "special populations" refers to those population groups in the United States that are at a higher-than-average risk of death, disease, and disability. These groups often need special targeted efforts. African Americans, Hispanics, Native Americans, persons older than 65, blue-collar workers, and low-income groups are all population groups identified as being medically underserved and having elevated health risks. These groups are specifically addressed with health objectives in *Healthy People 2000*.

However, significant national concern also exists about the health of rural populations. U.S. rural communities have lower income, higher poverty, and less education than their urban neighbors. They have higher rates of chronic illness and disability and report poorer overall health status than urban residents (National Center for Health Statistics 1985). In addition, rural residents have less access to health care services and are less likely to have health insurance. Because of the large proportion of low-income families, blue-collar workers, and medically underserved people residing in rural areas, rural populations are viewed as a special population. As described in Section I of this monograph, Appalachia has the burden of including large numbers of these special populations within its boundaries.

Year 2000 Objectives—The Development Process

The *Healthy People 2000* objectives were developed and agreed on by numerous organizations and took nearly 3 years to complete. Approximately 300 national organizations and representatives from all the state health departments joined the U.S. Department of Health and Human Services in this project. During the development process, regional and national hearings were held to solicit comments on the health promotion and disease prevention priorities of the next decade. *Healthy People 2000* represents the culmination of this process. The strength of the *Healthy People 2000* objectives stems from the fact that consensus was reached in defining the objectives at multiple levels of government and that the objectives were measurable. Chapter 16 of the report focuses entirely on cancer; other chapters on nutrition, tobacco, alcohol, educational and community-based programs, occupational safety and health, environmental health, oral health, and clinical preventive services all are related directly or indirectly to cancer.

In recent decades, it has become increasingly evident that most cancer is caused or promoted by lifestyle and environmental factors. Although research is advancing rapidly, genetic factors remain largely out of our control. In addition, changes in environmental conditions usually, though not always, require broad social action or system alteration. Therefore, lifestyle factors, because they are behaviors over which the individual has control, remain the focus of cancer prevention and control activities for NCI. These behaviors include tobacco and alcohol use, choice of diet, excessive exposure to sunlight, sexual behavior patterns, and use of cancer screening procedures.

As the year 2000 approaches, the key objectives for NCI are to:

- Reduce the percentage of adolescents and adults who use tobacco;
- Encourage change in individual diets to reduce the percentage of fat intake and to increase fiber intake by eating more fruits, vegetables, and whole grains;
- Increase the proportion of women receiving Pap tests and mammograms; and
- Increase the use of state-of-the-art cancer treatments and prevention and control activities.

The specific measurable objectives are outlined in Table 2.

Selected objectives from other *Healthy People 2000* priority areas relevant to cancer and rural populations are listed along with their chapter numbers in Table 3.

The objectives from other priority areas are important in three respects. First, they provide a measurable baseline for comparison and are useful in determining needs for communities. Second, the objectives provide a focal point for community and state action that can be scientifically defended. Third, from a review of the cancer-specific and related objectives, it becomes apparent that there are strong interrelationships and that community and state action must take into account these interrelationships.

Tracking Progress

Included in each chapter of *Healthy People 2000* is a section on surveillance and data needs. Surveillance serves the function of monitoring progress toward the attainment of objectives and indicates areas for increased or decreased activity. Often local communities and even states lack the requisite data systems to set baselines and track progress, so information must be extrapolated from national data. NCI's Surveillance, Epidemiology, and End Results Program (SEER) monitors the cancer burden on the population of the United States

TABLE 2

Healthy People 2000 *cancer objectives*

16.1*	Reverse the rise in cancer deaths to achieve a rate of no more than 130 per 100,000 people. (Age-adjusted baseline: 133 per 100,000 in 1987) **Note:** In its publications, the National Cancer Institute (NCI) age-adjusts cancer death rates to the 1970 U.S. population. Using the 1970 standard, the equivalent baseline and target values for this objective would be 171 and 175 per 100,000, respectively.
16.2*	Slow the rise in lung cancer deaths to achieve a rate of not more than 42 per 100,000 people. (Age-adjusted baseline: 37.9 per 100,000 in 1987) **Note:** In its publications, NCI age-adjusts cancer death rates to the 1970 U.S. population. Using the 1970 standard, the equivalent baseline and target values for this objective would be 47.9 and 53 per 100,000, respectively.
16.3	Reduce breast cancer deaths to no more than 20.6 per 100,000 women. (Age-adjusted baseline: 22.9 per 100,000 in 1987) **Note:** In its publications, NCI age-adjusts cancer death rates to the 1970 U.S. population. Using the 1970 standard, the equivalent baseline and target values for this objective would be 27.2 and 25.2 per 100,000, respectively.
16.4	Reduce deaths from cancer of the uterine cervix to no more than 1.3 per 100,000 women. (Age-adjusted baseline: 2.8 per 100,000 in 1987) **Note:** In its publications, NCI age-adjusts cancer death rates to the 1970 U.S. population. Using the 1970 standard, the equivalent baseline and target values for this objective would be 3.2 and 1.5 per 100,000, respectively.
16.5	Reduce colorectal cancer deaths to no more than 13.2 per 100,000 people. (Age-adjusted baseline: 14.4 per 100,000 in 1987) **Note:** In its publications, NCI age-adjusts cancer death rates to the 1970 U.S. population. Using the 1970 standard, the equivalent baseline and target values for this objective would be 20.1 and 18.7 per 100,000, respectively.

continued

TABLE 2 *(continued)*

Healthy People 2000 *cancer objectives*

SERVICES AND PROTECTION OBJECTIVES

16.10 Increase to at least 75 percent the proportion of primary care providers who routinely counsel patients about tobacco use cessation, diet modification, and cancer screening recommendations. (Baseline: About 52 percent of internists reported counseling more than 75 percent of their smoking patients about smoking cessation in 1986.)

16.11 Increase to at least 80 percent the proportion of women age 40 and older who have ever received a clinical breast examination and a mammogram, and to at least 60 percent those age 50 and older who have received them within the preceding 1 to 2 years. (Baseline: 36 percent of women age 40 and older "ever" in 1987; 25 percent of women age 50 and older "within the preceding 2 years" in 1987)

Special Population Targets

	Clinical Breast Exam and Mammogram:	1987 Baseline %	2000 Target %
	Ever Received		
16.11a	Hispanic women age 40 and older	20	80
16.11b	Low-income women age 40 and older (annual family income<$10,000)	22	80
16.11c	Women age 40 and older with less than high school education	23	80
16.11d	Women age 70 and older	25	80
16.11e	African-American women age 40 and older	28	80
	Received Within Preceding 2 Years		
16.11a	Hispanic women age 50 and older	18	60
16.11b	Low-income women age 50 and older (annual family income<$10,000)	15	60
16.11c	Women age 50 and older with less than high school education	16	60
16.11d	Women age 70 and older	18	60
16.11e	African-American women age 50 and older	19	60

16.12 Increase to at least 95 percent the proportion of women age 18 and older with uterine cervix who have ever received a Pap test, and to at least 85 percent those who received a Pap test within the preceding 1 to 3 years. (Baseline: 88 percent "ever" and 75 percent "within the preceding 3 years" in 1987)

continued

TABLE 2 *(continued)*

Healthy People 2000 *cancer objectives*

RISK REDUCTION OBJECTIVES

16.6* Reduce cigarette smoking to a prevalence of no more than 15 percent among people age 20 and older. (Baseline: 29 percent in 1987, 32 percent for men and 27 percent for women)

Special Population Targets

	Cigarette Smoking Prevalence	1987 Baseline (%)	2000 Target (%)
16.6a	People with a high school education or less age 20 and older	34	20
16.6b	Blue-collar workers age 20 and older	36	20
16.6c	Military personnel	42†	20
16.6d	African Americans age 20 and older	34	18
16.6e	Hispanics age 20 and older	33‡	18
16.6f	American Indians/Alaska Natives	42-70§	20
16.6g	Southeast Asian men	55♦	20
16.6h	Women of reproductive age	29■	12
16.6i	Pregnant women	25•	10
16.6j	Women who use oral contraceptives	36✣	10

†1988 baseline; ‡1982-84 baseline for Hispanics age 20-74; §1979-87 estimates for different tribes; ♦1984-88 baseline; ■Baseline for women age 18-44; •1985 baseline; ✣1983 baseline

Note: A cigarette smoker is a person who has smoked at least 100 cigarettes and currently smokes cigarettes.

16.7* Reduce dietary fat intake to an average of 30 percent of calories or less and average saturated fat intake to less than 10 percent of calories among people age 2 and older. (Baseline: 36 percent of calories from total fat and 13 percent from saturated fat for people age 20 through 74 in 1976 to 1980; 36 percent and 13 percent for women age 19 through 50 in 1985)

Note: The inclusion of a saturated fat target in this objective should not be interpreted as evidence that reducing only saturated fat will reduce cancer risk. Epidemiologic and experimental animal studies suggest that the amount of fat consumed rather than thespecific type of fat can influence the risk of some cancers.

16.8* Increase complex carbohydrate and fiber-containing foods in the diets of adults to five or more daily servings for vegetables (including legumes) and fruits, and to six or more daily servings for grain products. (Baseline: 2-1/2 servings of fruits and vegetables and three servings of grain products for women age 19 through 50 in 1985)

16.9 Increase to at least 60 percent the proportion of people of all ages who limit sun exposure, use sunscreens and protective clothing when exposed to sunlight, and avoid artificial sources of ultraviolet light (e.g., sun lamps, tanning booths). (no baseline data available at time of publication)

continued

TABLE 2 *(continued)*

Healthy People 2000 *cancer objectives*

	Special Population Targets		
	Pap Test	1987 Baseline %	2000 Target %
	Ever Received		
16.12a	Hispanic women age 18 and older	75	95
16.12b	Women age 70 and older	76	95
16.12c	Women age 18 and older with less than high school education	79	95
16.12d	Low-income women age 18 and older (annual family income<$10,000)	80	95
	Received Within Preceding 3 Years		
16.12a	Hispanic women age 18 and older	66	80
16.12b	Women age 70 and older	44	70
16.12c	Women age 18 and older with less than high school education	58	75
16.12d	Low-income women age 18 and older (annual family income<$10,000)	64	80

16.13	Increase to at least 50 percent the proportion of people age 50 and older who have received fecal occult blood testing within the preceding 1 to 2 years, and to at least 40 percent those who have ever received proctosigmoidoscopy. (Baseline: 27 percent received fecal occult blood testing during the preceding 2 years in 1987; 25 percent had ever received proctosigmoidoscopy in 1987.)
16.14	Increase to at least 40 percent the proportion of people age 50 and older visiting a primary care provider in the preceding year who have received oral, skin, and digital rectal examinations during one such visit. (Baseline: An estimated 27 percent received a digital rectal examination during a physician visit within the preceding year in 1987.)
16.15	Ensure that Pap tests meet quality standards by monitoring and certifying all cytology laboratories. (no baseline data available at time of publication)
16.16	Ensure that mammograms meet quality standards by monitoring and certifying at least 80 percent of mammography facilities. (Baseline: An estimated 18 to 21 percent certified by the American College of Radiology as of June 1990)
	*Reverse the increase in cancer deaths to achieve a rate of no more than 130 per 100,000 people (Age-adjusted baseline: 133 per 100,000 in 1987)

Source: Adapted from *Healthy People 2000,* U.S. Department of Health and Human Services 1991.

TABLE 3

Selected Healthy People 2000 *objectives*	
	Nutrition
2.5	Reduce fat intake to an average of 30 percent of calories or less and average saturated fat intake to less than 10 percent of calories among people age 2 and older.
2.6	Increase complex carbohydrate and fiber-containing foods in the diets of adults to five or more daily servings for vegetables (including legumes) and fruits and six or more daily servings of grain products.
	Tobacco
3.9	Reduce smokeless tobacco use by males age 12 through 24 to a prevalence of no more than 4 percent.
	Alcohol and Other Drugs
4.8	Reduce alcohol consumption by people age 14 and older to an annual average of no more than 2 gallons of ethanol per person.
	Educational and Community-Based Programs
8.1	Increase years of healthy life to at least 65 years.
	Occupational Safety and Health
10.11	Establish in 50 states exposure standards adequate to prevent the major occupational lung diseases to which their worker populations are exposed (byssinosis, asbestosis, coal worker's pneumoconiosis, and silicosis).
	Environmental Health
11.6	Increase to at least 40 percent the proportion of homes in which homeowners/ occupants have tested for radon concentrations and that have been found either to pose minimal risk or to reduce risk to health.
	Oral Health
13.7	Reduce deaths due to cancer of the oral cavity and pharynx to no more than 10.5 per 100,000 men age 45 through 74 and 4.1 per 100,000 women age 45 through 74.
	Clinical Preventive Services
21.6	Increase to at least 50 percent the proportion of primary care providers who provide their patients with the screening, counseling, and immunization services recommended by the U.S. Preventive Services Task Force.

Source: Adapted from Healthy People 2000, U.S. Department of Health and Human Services 1991.

through the measurement of cancer incidence, mortality, and survival and the assessment of individual and societal factors that mediate these measures. Ultimately, cancer surveillance guides future programmatic decisions of NCI and reflects any shifts in cancer incidence and mortality brought about through improvements in early detection, prevention, and treatment. Surveillance figures can reveal progress or continuing challenge and the need for focused attention among the vast diversity of cancers. To this end, the surveillance effort includes the development of information and statistical analysis systems, such as population-based registries and national probability surveys, as well as a broad series of studies using specific cancer control indicators. Programmatically and operationally, cancer surveillance requires a strong interface between methodologic techniques and cancer control initiatives in prevention, early detection, and treatment. Unfortunately, most available data systems lack sufficient sample size to represent the Appalachian region accurately. However, these data systems do provide fairly accurate indicators and can be used in state and community planning efforts.

NCI's SEER consists of 10 population-based cancer registries covering 10 percent of the nation's population. It is the major system for tracking cancer incidence, patient survival, and mortality in the United States. The data are coupled with information on cancer risk factors, prevention practices, and patterns of cancer care. Linkage of SEER's tumor registry data with medicare files has produced several reports on costs by cancer site and stage as well as by treatment phase. Geographic and demographic differences in incidence, survival, and mortality are being studied to reveal factors associated with improvements in cancer risk, including the availability of cancer prevention and control programs. The results of SEER research are available to the entire cancer research community and are published on a periodic basis.

Another useful tracking system is NCI's participation in the National Health Interview Survey (NHIS). This survey, conducted annually by the National Center for Health Statistics (NCHS), is a national probability sample derived from personal interviews with adults in approximately 44,000 U.S. households. NHIS has long been known to have one of the highest response rates of any national survey. In 1991, NCI contracted with NCHS to add a Cancer Control Supplement to its 1992 NHIS with special emphasis on the Hispanic population. This supplement provided for the collection of knowledge, attitudes, and behavior data on smoking and tobacco use, cancer screening practices, and dietary practices; it was comparable to the 1987 benchmark NHIS. The 1992 NHIS supplement expanded content areas on medical care, physician practice, cancer survivorship, and frequency of intake of specific foods. Analysis and publication of findings from the 1992 NHIS will provide data on various cancer control issues and will be used for planning and directing future cancer control activities. NHIS and SEER data are available through state health departments or can be obtained by contacting NCI directly.

Recent cancer trends are attributable in part to the National Cancer Program that was established by the National Cancer Act in 1971. The act was based on the report of a national panel of consultants titled "A National Program for the Conquest of Cancer." The act provided special authorities including the Bypass Budget, presidential appointment of the NCI Director, and establishment of the National Cancer Advisory Board, also appointed by the President. The intent of the act was to provide more resources for cancer research and to remove some bureaucratic obstacles. With each reauthorization, directives have been added.

In addition, the Centers for Disease Control and Prevention provides funds to states for the Behavioral Risk Factor Surveillance Survey. Conducted by individual states, this telephone

survey tracks a number of behavioral risk factors and is especially useful because it provides state-level data rather than national data and thus is more representative of the population being surveyed.

Cancer Risk Factors

NCI-supported research estimates that roughly 80 percent of cancers are related to lifestyle and environmental factors, making most cancers preventable in principle. Tobacco use, for example, accounts for an estimated 30 percent of all cancer deaths; dietary factors, meanwhile, are implicated in about 35 percent of all cancer cases. NCI has responded to the need for expanded research in these areas by developing a diverse array of programs. In the sections that follow, risk factors for cancer are identified. These risk factors are highlighted in *Healthy People 2000* under the general category of risk reduction objectives, which are of primary importance to community programs because they provide a basis for action and indicate national baselines for comparison and measurement of progress.

Tobacco Use

Cigarette smoking is the major cause of lung cancer and an important risk factor for cancers of the oral cavity, pharynx, larynx, esophagus, bladder, kidney, and pancreas. Recent studies also have suggested a relationship of smoking to other cancers, including those of the nasal passages, stomach, liver, and prostate as well as leukemia. Research is under way to clarify the possible relationship of alcohol intake and tobacco use to breast and colorectal cancers. In some parts of the nation, particularly in rural areas, the use of smokeless tobacco (snuff) accounts for a substantial portion of oral cancer. As tobacco products are responsible for one-third or more of all cancers in the United States, studies will continue to define tobacco-related cancers, interactions of smoking and other possible cancer risk factors, and the extent of risk associated with various forms of tobacco exposure, including involuntary smoke inhalation (passive smoking).

The National Cancer Institute's most recent response to this overwhelming public health problem was to initiate the American Stop Smoking Intervention Study for Cancer Prevention (ASSIST). ASSIST represents a collaborative effort between NCI and ACS along with state and local health departments and other voluntary organizations to develop comprehensive tobacco control programs in 17 states. Its purpose is to demonstrate that the widespread, coordinated application of the best available strategies to prevent and control tobacco use will accelerate the current downward trend in smoking and tobacco use significantly. The result is expected to be substantial reduction in the number and rate of tobacco-related cancers in the United States. The ASSIST intervention model is based on proven smoking prevention and control methods developed within NCI's intervention trials and other smoking and behavioral research. Swan and Goss (this volume) discuss the ASSIST intervention and other NCI coalition programs.

Diet and Nutrition

Diet and nutrition are increasingly recognized as likely to be major determinants in the etiology of cancers, notably those of the gastrointestinal tract, breast, endometrium, ovary, and prostate. Indeed, dietary factors collectively may account for a greater portion of all cancers occurring in contemporary Western society than does any other category of environmental exposure. Recent studies estimate that 35 percent of certain types of cancers are related to diet. This research is examining international variations of cancer incidence in which the cancer incidence rates of immigrants approach those of the resident population of the host country during the process of acculturation. In addition, several epidemiological projects are under way to evaluate the role of diet and nutrition in can-

cers of the lung, esophagus, stomach, large bowel, breast, endometrium, ovary, cervix, and other sites. The thrust is to identify and clarify specific dietary constituents and nutritional mechanisms that may be involved in cancer etiology. Interactions among diet, obesity, and caloric expenditure also are being evaluated. Thus far, much of this research suggests an inverse relationship between physical activity and risk of colorectal cancer. The mechanisms underlying this association are now under investigation.

Several trials are examining the role of diet and cancer prevention. NCI is conducting the Women's Health Trial as a 3-year pilot study to test methods to enable African-American, Hispanic, and low-income populations to change their current eating habits (about 37 percent of calories from fat) to a low-fat eating pattern (20 percent of calories from fat). This study also will evaluate the effect of social customs, culture, and economic status on achieving and maintaining this dietary pattern and increasing the consumption of dietary fiber, fruits, vegetables, and grain products. The trial results will be used in the design of interventions for the National Institutes of Health (NIH) Women's Health Initiative, a national study of diet, supplements, and hormone replacement therapy. The overall goal of this research is to provide more definitive data for developing quantitative dietary guidance for desirable eating patterns and food choices that have the potential for a substantial reduction in cancer risk in the general population.

Alcohol

Alcohol is a risk factor for primary liver cancer as well as for certain head and neck cancers (National Research Council 1982). In addition, it combines with tobacco smoking to increase risk for most cancers of the oral cavity, pharynx, esophagus, and larynx among Americans. In a nationwide study, high use of cigarettes and alcohol resulted in a 35-fold greater risk of oral and pharyngeal cancers. This study also found that, even among nonsmokers, the risk of these cancers rose with increasing alcohol consumption, suggesting that alcohol itself is carcinogenic in humans. A study of coastal South Carolina residents implicated excessive consumption of illegally produced whiskey ("moonshine") in the longstanding elevation of esophageal cancer rates among African-American males living in the area. Studies will continue to evaluate the independent cancer risks associated with alcohol consumption and its effects in combination with other factors such as nutritional deficiencies. Recent NCI epidemiologic research also reports significant increases in the rate of alcohol-related esophageal cancer among inner-city African Americans.

Sexual Practices and Pregnancy

A number of cancers have been linked to sexual practices and certain lifetime patterns of pregnancy. Multiple sexual partners, early sexual activity, prior genital infections, and extended use of oral contraceptives are among the risk factors for cervical cancer. In high-risk areas of Latin America, the sexual habits of husbands were linked to cancer risk. The relationship of sexual activity to cervical cancer and to other cancers of the anogenital region appears related to the presence of human papillomavirus (HPV), especially the sexually transmitted types 16 and 18. In a recent study of penile cancer in a high-prevalence area of China, risk factors included poor personal hygiene, premarital or extramarital sexual relations, warts, and other genital diseases. In addition, high parity has been associated with an excess risk of cervical cancer. Women having 10 or more births appear to be at a higher risk than those having fewer births. On the other hand, increased risks for cancer of the breast, ovary, endometrium, and colon among women have been associated with low parity. The role of pregnancy as well as sexual practices will continue to be investigated in epidemiologic studies.

Sexual transmission of certain viruses has been implicated in the risk for various other cancers. For example, adult T-cell leukemia has been linked to the human T-cell lymphotropic virus type 1 (HTLV-1), which can be transmitted sexually. Sexual practices also may affect transmission of hepatitis B virus and increase the subsequent risk of primary liver cancer. Sexual practices among homosexual men may involve the transmission of viruses that have been linked to increased risks of AIDS-related cancers, notably Kaposi's sarcoma and non-Hodgkin's lymphoma.

Sunlight

Exposure to ultraviolet radiation from sunlight is thought to be the major environmental cause of various skin cancers, including the more common melanoma and nonmelanoma types. The upward trend in melanoma incidence appears to be linked mainly to sunlight exposure from lifestyle patterns, such as recreational exposures and changes in clothing habits. Skin cancer is the most common form of cancer in the United States; 600,000 new cases are reported every year. An estimated 9,100 deaths this year will be attributed to skin cancer—6,800 from malignant melanoma and 2,300 from other skin cancers. Between 1973 and 1989, the incidence rate for melanoma increased by almost 81 percent, more than for any other cancer site and far more than the 16-percent increase for all sites combined. The mortality rate for melanoma during this same period was 32 percent. However, most skin cancer morbidity and almost all skin cancer mortality should be preventable. Solar radiation appears to be the primary risk factor for more than 90 percent of nonmelanoma skin cancer cases, and it has been linked to melanoma. Overall, data appear to indicate that nonmelanoma skin cancer is related to cumulative exposure and that melanoma may be related to high-intensity, intermittent ultraviolet radiation, particularly among children. An NCI collaborative case-control study in Denmark indicated the importance of sunlight exposure in childhood as well as sun sensitivity and sunburning associated with fair skin color and complexion as important factors in the risk of melanoma. NCI and ACS continue in their efforts to educate the American public and health care providers about the danger of ultraviolet radiation.

Occupation and Environment

As Doll and Peto (1981) point out, it is difficult to determine the proportion of cancers today that are attributable to occupational hazards. Perera and colleagues caution that the risk of cancer is determined by complex interactions among "environmental exposures, genetic, and nutritional factors that modulate an individual's response to carcinogens" (Perera et al. 1990, p. 639). They define "environment" broadly to include lifestyle, occupation, and the ambient environment. We are just beginning to understand the full range of health effects resulting from exposure to occupational and environmental factors. The most convincing and consistent evidence relates to the risk of developing lung cancer where as much as 15 percent of lung cancer in men and 5 percent in women can be attributed to occupational exposures (Doll and Peto 1981). The best estimate to date is that 4 percent of all U.S. cancer deaths are attributed to occupation. However, individuals who are employed in occupations that involve the use of carcinogenic agents have an increased risk for certain types of cancer. For example, studies in the United States and other countries have shown that farmers have a higher risk of cancers of the blood and the immune system (leukemia, non-Hodgkin's lymphoma, and multiple myeloma). The reasons for the increased risks are not clear, and scientists are looking at chemical (e.g., pesticides, herbicides) and other occupational exposures common to farming to identify the possible causes of cancer.

Several notable accomplishments over the past decade should provide the groundwork for environmental and occupational public health action in the future: identification of probable environmental risks, development of methods for monitoring exposure and effects, and educating the public about effective prevention measures.

Screening and Detection

Early detection has particular relevance in terms of improved treatment and survival for cancers of the breast, skin, uterus/cervix, colon/rectum, testis, prostate, and oral cavity. The effectiveness of screening for breast and cervical cancers in reducing morbidity has been scientifically established. Screening for breast cancer can reduce breast cancer mortality among women age 50 and older, yet only 47 percent of women in this age group have received a clinical breast exam and mammography within the past 2 years. Similarly, use of the Pap test to screen for cervical cancer greatly reduces the risk of death. However, results from the most recent NHIS suggest that a significant portion of women are not receiving Pap tests regularly, particularly older women still at risk.

Colorectal cancer is expected to account for 152,000 new cases and 57,000 deaths in 1993. Screening tests such as rectal examination, proctoscopy, and colonoscopy should be performed for patients who are at higher risk of cancer, for example, people older than 40; those who have a family history of cancer of the colon, rectum, or female organs; and those who have a history of ulcerative colitis (ulcers in the lining of the large intestines).

Cancer Prevention and Control Interventions

The *Healthy People 2000* objectives can be attained only through a strong, effective partnership among government at all levels, professional groups, voluntary organizations, health researchers, private industry, and the media—in short, all sectors of society. Achieving the lifestyle changes called for by the objectives will be a challenge; it has taken 35 years since the first report of the surgeon general to reduce smoking prevalence by 32 percent. To achieve change, no single approach or communications channel may be sufficient. Multiple messages and interventions that are well coordinated and reinforced are essential. Chapter 8 of the full report of *Healthy People 2000* notes the following:

> *The most effective community-based health promotion programs recognize the interrelationships between behavior and the environment and include multiple interventions directed at multiple levels (e.g., individuals, small groups/families, organizations, community) (U.S. Department of Health and Human Services 1991).*

NCI's program of research and application has been based on these principles. The structure of the National Cancer Program was designed to achieve the same goals that the *Healthy People 2000* objectives now express. A system of basic research, clinical trials, and applications research, with the collaboration and cooperation of governmental and nongovernmental agencies and organizations, is working to promote cancer prevention and control activities across the country. In light of this experience, NCI has incorporated a variety of different intervention strategies and intervention channels in its research.

Cancer Information Dissemination

The intensified, expanded program of cancer research over the past 20 years created a knowledge base for application to the cancer problem. NCI has become more aggressive in reaching out to health professionals, cancer patients, and the general public to make sure that they are aware of and can benefit from important research findings. Outreach to underserved populations—the old, the poor, people of low literacy, and minorities—has

become increasingly important because they have not benefited as much as others from the newly generated knowledge. In addition, community service and outreach are a crucial element in the NCI Cancer Centers Program. All NCI's information dissemination activities are research-based to evaluate critically the efficacy of the methods used and, in turn, to enhance the dissemination of knowledge to the diverse audiences who can benefit.

In 1993, NCI substantially restructured and revitalized the Cancer Information Service (CIS) program through a new program structure that divides the country into 19 geographical regions. The new structure maintains the three primary program components: operation of a toll-free telephone service, development of local resource directories of cancer-related services and programs for each region, and development and implementation of cancer information and education programs for each region. The toll-free telephone service is the largest component of the CIS program; it provides accurate, up-to-date cancer information to patients and their families, health professionals, and the general public. Since its inception in 1976, CIS has handled more than 4 million inquiries and currently receives more than 600,000 calls per year. Swan and Goss (this volume) further discuss CIS.

The Patient Education Program is responsible for developing, promoting, and evaluating state-of-the-art education and information programs enabling cancer patients and their families to receive state-of-the-art care, participate fully in treatment and care decisions, and achieve the best possible quality of life. The program targets cancer patients and their families, and these groups are delineated further based on specific program initiatives. Consideration is given to elderly persons, minority audiences, low-literacy groups, and special age groups such as pediatric, adolescent, and adult patients. Health care professionals who work with cancer patients and their families in medical settings are also target groups.

Several NCI intervention research efforts have the potential to affect the Appalachian population.

Regional Breast Cancer Summits

In conjunction with the Susan G. Komen Breast Cancer Foundation, NCI is cosponsoring eight regional Breast Cancer Summits at NCI-designated comprehensive cancer centers. The summits are designed to bring together and encourage community organizations and local businesses to provide education and screening programs for their members and employees.

Once-A-Year Mammography Education Program

NCI has developed a broad-based mammography education program titled "Once A Year...For A Lifetime." The program has been the basis of numerous education activities implemented by other federal, state, and local government agencies; local community groups; service organizations; churches; local health facilities; and others. Program materials are available for distribution and use with women age 40 and older, the media, and community groups.

Low-Literacy Education Programs

One of the newest NCI special population efforts is the Low-Literacy Program, which is communicating cancer prevention, early detection, and treatment information to individuals with limited education. Researchers have hypothesized that people with limited literacy may lack essential information regarding their health and may not be able to follow a physician's instructions adequately. In addition, most available cancer education materials are written for the 10th-grade reading level or above and are not appropriate for these individuals. It is also well documented that people of low socioeconomic status suffer disproportionately high levels of cancer inci-

dence and mortality; in turn, these individuals are more likely to smoke and less likely to be screened for breast and cervical cancers.

Physician Data Query and CANCERLIT

Physician Data Query (PDQ) is a computer database of cancer treatment information and early detection guidelines. It contains up-to-date information about treatment; clinical trials in progress; physicians who treat cancer, by geographic area and specialty; and hospitals that have cancer programs. In 1993, CIS will initiate service on a new toll-free telephone number to expand physician access to PDQ. The toll-free number will allow physicians to request information from the database customized to their individual needs. Physicians serving primarily disadvantaged and underserved populations and others who do not have access to personal computers will be able to request a search geared to individual patient needs or to find out what clinical trials are being done in an area of research interest.

CANCERLIT is an online cancer information database accessed through the National Library of Medicine.

American Stop Smoking Intervention Study for Cancer Prevention

Initiated in 1991, ASSIST is conducted in association with the American Cancer Society through contracts with state public health agencies. The study incorporates research findings of previous NCI tobacco control trials and demonstrates the application of effective interventions on large-scale populations over a 7-year period (1991 to 1998). ASSIST is currently being implemented in 17 states involving more than 91 million Americans (20 million smokers). These states are Colorado, Indiana, Maine, Massachusetts, Michigan, Minnesota, Missouri, New Jersey, New Mexico, New York, North Carolina, Rhode Island, South Carolina, Virginia, Washington, West Virginia, and Wisconsin. Together, these states include 10.3 million African Americans, 4.3 million Hispanics, 2 million Asians and Pacific Islanders, and 600,000 Native Americans. It is estimated that ASSIST will result in the prevention of more than 1.2 million premature deaths caused by tobacco use, including nearly 500,000 lung cancer deaths.

Health Department Data-Based Intervention Research Program

The Health Department Data-Based Intervention Research Program builds the foundation for ongoing cancer control programs within state health departments. These programs ensure the translation of cancer prevention and treatment science into practice across the United States. Since the program's initiation in 1987, 30 programs have received funding to analyze available data to develop state cancer control programs and begin the implementation and evaluation of high-priority cancer control interventions that meet the unique needs of each state.

National 5-A-Day for Better Health Program

The national 5-A-Day for Better Health program, designed to encourage Americans to eat five or more servings of fruits and vegetables every day, was initiated during fiscal year 1992. It is a joint project of NCI and the Produce for Better Health Foundation and is the largest public/private enterprise ever undertaken by NCI.

Over the next 5 years, the national 5-A-Day for Better Health program will encourage all Americans to eat five servings or more of fruits and vegetables a day as part of a low-fat, high-fiber diet; award 4-year research grants to evaluate the effect of 5-A-Day activities in schools, workplaces, and other community settings; and work with the Produce for Better Health Foundation, which represents more than 200 food retailer organizations and more than 30,000 supermarkets, to promote the program's message in the marketplace.

Science Enrichment Program

In early 1989, the Science Enrichment Program was developed as a 2-year pilot

program to address the critical need to replenish the supply of health scientists and health professionals that will be required for the future. The long-range goal of this program is to encourage underrepresented minority and underserved youth—African Americans, Hispanic Americans, and Native Americans (American Indians, Alaska Natives, and Native Hawaiians)—as well as individuals from low-income backgrounds to pursue professional careers in science research fields.

Conclusion

As we prepare to enter the 21st century, the *Healthy People 2000* initiative offers a vision of dramatic reductions in preventable death and disease, improved quality of life, and reduced disparities of health status among our population segments. It is important to note that this initiative is national in scope but dependent on local action.

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CHAPTER 6

Action Steps

1. Create strong and effective local partnerships among all levels of government, health professionals, lay groups, voluntary organizations, schools, community institutions, health researchers, health educators, local businesses, citizen groups, and the media.

2. Use these partnerships and coalitions to reach underserved populations and to promote initiatives to attain the health objectives expressed in *Healthy People 2000.*

3. Listen and respond to the cancer-related needs, concerns, and problems expressed by local residents of both the professional and lay communities.

4. Identify and address lifestyle and environmental factors in the local area that contribute to an increased risk of cancer, such as tobacco and alcohol use, diet, sexual practices, sun exposure, and occupational and environmental risks.

5. Launch collaborative efforts to develop comprehensive tobacco and alcohol control programs.

6. Evaluate the role of diet in cancer prevention, and develop quantitative dietary guidelines applicable to the local area that could reduce the risk of cancer.

7. Increase access to clinical screenings and cancer detection services. In particular, increase the portion of high-risk populations receiving tests that screen for cancer of the breast, uterus/cervix, colon/rectum, testis, prostate, skin, and oral cavity.

8. Call on local organizations, coalitions, and citizen groups to help develop educational materials and implement programs that increase the public's knowledge about cancer prevention, detection, and treatment. Educational materials should be tailored to the target population and the education level of the group.

9. Use risk reduction objectives expressed in *Healthy People 2000* as a basis for action and a baseline for comparison and measurement of local efforts. Use existing networks to assess current incidences of cancer and its contributing causes. Develop a method for data collection and tracking change.

10. Identify local probable risk factors, develop methods for monitoring exposure and effects, educate the public about prevention measures, and implement multiple intervention efforts directed toward various audiences.

CHAPTER 7

Socioeconomic Status and Cancer

Richard A. Couto, Cheryl S. Schott, and Neal Richard Boyd

Introduction

As early as the 12th century, individuals in low social and economic positions or of low socioeconomic status (SES) were reported to have higher rates of illness and death (Kaplan et al. 1987). Although the relationship among income, class, race, gender, education, and the other factors that make up SES and health is well recognized, the mechanisms of that relationship are seldom explained. Although we know that SES and health are linked, we do not know how the links are forged.

This chapter discusses the association of SES and health as well as the association of SES and cancer. It also reports on efforts to identify and analyze the specific components of SES that are linked to cancer incidence, mortality, and survival. The Appalachia Leadership Initiative on Cancer (ALIC) program is targeting rural communities in Appalachia, communities more likely to have lower levels of SES within a region whose SES level is lower than the national average. Consequently, ALIC projects will be operating in the uncertain territory where SES and cancer intersect.

SES and Health

The connection between people's social and economic position in society and their health is pervasive and profound (Haan et al. 1989, p. 106). Regardless of whether a disease is acute or chronic or how SES is measured, we find disparities in illness, mortality, and survival rates among people of different SES levels in all countries (Kaplan et al. 1987). The relationship appears at the national level as well. For example, Americans spend more money on health care during periods of poor economic growth (Hurowitz 1993, p. 131). The breadth of these health differences among SES groups varies from nation to nation. Likewise, the differences may vary in the same nation and within regions of nations. Whatever the variation, however, health differences among SES groups coincide with the distribution of income. Where the distribution of income is equal or nearly so, health differences among its recipients are narrow (Hurowitz 1993, p. 132).

The effect of SES on health is profound. Disparities in health among different SES groups remain over time despite changes in other factors. Advances in medical care and standards of living, for example, may increase the overall life expectancy of a nation's citizens or decrease the overall incidence of a disease, but disparities among SES groups remain. Even access to medical intervention advances occurs among SES groups at different rates.

There is a health gradient among SES groups as well. Not only are the rich healthier than the poor, but also the rich are healthier than the middle class and members of the middle class are healthier than the poor (Haan et al. 1989, pp. 82, 93-97). The findings of diverse studies over a long period suggest "a pervasive

TABLE 1

Death rates in 1986 among persons 25 through 64 years old in selected education and income groups according to race and sex*

	Deaths per 1,000			
	White		Black	
	Men	Women	Men	Women
Education *(Years completed)*				
School 0-11	7.6	3.4	3.4	6.2
12	4.3	2.5	8.0	3.9
College 1-3	4.3	2.1	5.0	3.2
>4	2.8	1.8	6.0	2.2
Income				
<$9,000	16.0	6.5	19.5	7.6
$9,000-$14,999	10.2	3.4	10.8	4.5
$15,000-$18,999	5.7	3.3	9.8	3.7
$19,000-$24,999	4.6	3.0	4.7	2.8
>$25,000	2.4	1.6	3.6	2.3

**Age-adjusted death rates were calculated from age-specific death rates with the entire U.S. population in 1940 used as the standard. Data are from the 1986 National Mortality Followback Survey and the 1986 National Health Interview Survey.*

and consistent relationship between SES and health...that is found throughout the life course and across a wide variety of disease and organ systems" (Haan et al. 1989, p. 80).

The United States offers ample evidence of the relationship between SES and health and of the health disparities among SES groups. In fact, the U.S. Department of Health and Human Services in *Healthy People 2000* (the report discussed in Chapter 6) asserted that "perhaps no challenge is more compelling than that of equity" for the coming decade in health (U.S. Department of Health and Human Services 1991, p. 31). This assertion stemmed from the following disparities observed among Americans (U.S. Department of Health and Human Services 1991, pp. 29-31).

► People with income below the poverty level have death rates that are twice the rates for people with incomes above the poverty level.

► Low income is associated with the leading chronic disease killers, heart disease and cancer.

► Low income is strongly associated with HIV infection and tuberculosis.

► Low income is strongly associated with death and injury by accidents and violence.

► Low SES is strongly associated with problem pregnancy outcomes including prematurity, low birth weight, birth defects, and infant mortality.

The inverse relationship between SES level and mortality is well documented (Pappas et al. 1993). It holds for both men and women and for whites and African Americans. For example, as shown in Table 1, in 1986, U.S. death rates fell with increasing levels of education and income for white men and black men as well as for white women and black women.

Although death rates have declined, disparities in mortality rates for various SES groups appear to be increasing. One recent study concluded:

> *As [U.S.] death rates have declined [since 1960], poor and less educated people have not benefitted equally in comparison with those who are wealthier and better educated. These differences are not confined to persons in extreme poverty but are seen across the socioeconomic spectrum (Pappas et al. 1993, p. 108).*

To explain the link between SES and health, researchers generally focus on particular elements of SES and analyze them for their relationship to health. Education and income, for example, are often used to differentiate SES groups, as Table 1 reports. Race and ethnicity are sometimes used as surrogate measures of SES because some groups are disproportionately represented in an SES group. For example, a larger portion of African Americans are in the lower income groups than in the general population (Baquet et al. 1991). In addition to income, education, and race and ethnicity, other measures of SES commonly used to assess its link to health and illness include place of residence, population density, occupation, access to care, form of health care (e.g., public or private hospitals), medical insurance, and transportation.

How SES and Illness are Related

SES, especially income, affects different forms of health and illness in various ways at different stages of a person's life. For example, SES affects health in infancy and childhood through the mother's risk of problem pregnancies and birth outcomes, which are higher among those with low income. In adolescence and early adulthood, low SES increases the risk of death from intentional and unintentional injuries. Beginning at age 40, chronic illnesses begin to take their toll on the health and lives of Americans. The prevalence of arthritis, heart disease, ulcers, diabetes, high blood pressure, chronic bronchitis, emphysema, gallbladder disease, and cancer increases as income decreases. Cancer becomes 30 times more common in women and 100 times more common in men as age increases from 25 to 75 (Doll 1991, p. 676). Low SES increases the risk to older people for many forms of cancer and decreases individuals' chances for survival. Disability related to illness is also higher among older people with low SES (Haan et al. 1989, pp. 77-80). Thus, SES, especially income, is related to an individual's health over the course of a lifetime.

SES and illness are related in several different ways (Haan et al. 1989, pp. 82-93). First, poor health may cause low SES. For example, mental illness can lower SES through its effect on employment and income. Mental illness has contributed to America's burgeoning homeless population; an estimated one-third of America's homeless have mental illness (National Institute of Mental Health 1991). Poor health also may affect SES through a "drift" factor; as some people age or suffer from debilitating disease, their incomes decline and their occupational status changes (Garber 1989).

This effect of health on SES explains a small portion of the interrelationship (Pappas et al. 1993, p. 108). However, SES more often affects health than vice versa. For example, low SES groups often have higher levels of unhealthful behaviors, such as smoking and alcohol consumption, that in turn are linked to poor health status. Tobacco use especially is linked to both cancer and SES. Although

tobacco use has declined in general, it has remained unchanged since 1966 among those who have completed 12 years or fewer of schooling. In addition, blue-collar workers report rates of smoking that are 20 percent higher than among other workers (U.S. Department of Health and Human Services 1991, p. 31). Low income is associated with higher-than-average rates of obesity and high blood pressure, both of which are linked to heart disease and stroke.

Some explanations attempt to link SES to health through a culture of poverty (Haan et al. 1989, p. 92). For example, "fatalism" is an attribute frequently applied to low-income Appalachian residents that is used to explain their attitudes about health, as discussed in Chapters 1 and 3. However, as these chapters explain, people do not maintain cultural attitudes unless the attitudes serve some purpose. People develop culture through their interactions with their environment, including the institutions with which they must deal. Differences in belief systems are more safely attributable to differences in group life experiences than to independent cultural or psychological factors of one group of people. If low-income individuals have different attitudes toward health and health behavior, it is most likely learned behavior and a reasonable response to their situation.

SES affects health because poor people have fewer of the material goods and services that produce good health. Quality transportation, housing, public sanitation, environment, nutrition, and other factors improve the health of individuals. Those who have more of these factors have better health not only because of the direct effect of these goods and services but also because of their indirect effect. For example, a person's sense of security and sense of control increase with higher levels of SES. Individuals at higher SES levels are better able to meet primary human needs, such as freedom from violence, adequate income, and suitable housing. Among the goods and services that vary with SES is medical insurance. Without medical insurance, low-SES individuals face formidable financial barriers to acquiring health care. Even with insurance, they find health care providers less readily available in areas with high concentrations of poverty, such as some parts of Appalachia, as explained in Chapter 4.

Finally, low SES may affect health because very low incomes require some people to live in areas of violence or environmental degradation and also to work at jobs that expose them to health risks (Haan et al. 1989, pp. 98-103). These risks range from emotional stress to toxic exposures.

The strong bond between SES and health is a knot in a chain. In it are tangled links of several SES factors that affect and are affected by health. For example, poverty is associated with significant childhood developmental limitations, and poor health negatively affects childhood development and educational attainment (U.S. Department of Health and Human Services 1991). One- and two-year-old children in low-income families were found to have twice the national average of iron deficiency. Growth retardation affects 16 percent of low-income children under age 6. Almost all American children at risk for mentally and physically impaired development because of blood lead levels come from low-income families. Poor children also have more sickness from infection and other debilitating conditions than children in families with more income (U.S. Department of Health and Human Services 1991, p. 30). Poverty retards the healthy development of children and, as a result, impedes educational attainment and job opportunities. However, although a portion of the relationship between SES and health is explained by poor health leading to loss of income, lower paying jobs, or poor educational attainment, more often low SES is a preceding influence on poor health.

The Demands-Resource Model

We have explained that people of lower SES face greater demands from their physical and social environments and have fewer resources to deal with these demands (Kaplan et al. 1987). The gap between demands and resources may lead to the acquisition and maintenance of high-risk health behaviors, such as smoking and drinking, as a means of coping with unavoidable demands. This gap also may explain the alleged cultural traits of the poor. For example, people without the means to pay for health care may do without it and defend their refusal to seek access with assertions about the medical system's inefficacy. This behavior illustrates the links among beliefs, behaviors, and resources. These demands-resources explanations relate SES and illness and combine and integrate several aspects of SES—income, resources, beliefs, and behaviors (Haan et al. 1989, p. 105).

The demands-resources model also explains why SES factors appear to cluster for their effects. For example, individual neighborhood characteristics may have no apparent association with illness, but, when combined with other characteristics, they show a relationship. Specifically, census tracts with high portions of men over age 65, widowers, persons without cars, deteriorated housing, and housing without heat are associated with high rates of cardiovascular mortality, mortality from all causes, and the incidence of cancer (Haan et al. 1989).

Not surprisingly, education and income stand out among the factors that link SES and health. If we compare mortality rates for people in different SES groups who have the same habits of smoking, alcohol consumption, physical activity, relative weight, and amounts of sleep, those with less education and lower income have higher mortality rates. Tobacco abstinence, moderation in alcoholic consumption, increased physical activity, weight control, and adequate rest promote good health. However, income and education affect health status despite healthful or high-risk behaviors (Haan et al. 1989, pp. 86-87).

There is no "big bang" theory to explain the origins of illness as the result of SES. On the contrary, it is the interaction among various specific factors of SES that affects an individual's health status. This includes the interaction between the physical and social environment, health risk behaviors, and health beliefs on one side and income and education on the other (Haan et al. 1989, pp. 104-105).

SES and Cancer

As we might expect, explanations of the link between SES and cancer resemble explanations of the link between SES and health in general. For example, SES seems to have a strong independent relationship with lung cancer. Studies have shown higher levels of lung cancer among smokers who have less education, lower occupational grade, and less income than other smokers (Haan et al. 1989, pp. 86-87).

However, two aspects of the SES and cancer link distinguish their relationship from those we have already examined. First, studies of SES and cancer have examined cancers in general and in particular. They attempted to correlate various SES factors with cancers in different parts of the body, such as lung and bronchus, stomach, colon, or rectum. Some cancer sites are gender-specific, for example, the breast and uterine cervix in women and the prostate gland in men. SES and cancer studies also may examine different aspects of cancer, for example, incidence, time of survival, and mortality.

A second difference occurs because we derive much of what we know about SES and cancer from studies about race and cancer. In 1973, a landmark study reported a significant disparity in the incidence and survival of cancer rates between African Americans and whites (Henschke et al. 1973). Although

cancer incidence and mortality rates had increased for both African Americans and whites over the previous two decades, they had increased more for African Americans than for whites, an early indication of a wider health disparity gap. With the release of the 1973 report, many researchers turned their attention to investigating racial differences in cancer incidence, mortality, and survival to confirm and elaborate the report's findings (Freeman 1989, 1991; Pamies and Woodard 1992; Mansfield 1992; Cella et al. 1991; Baquet et al. 1991; Boring et al. 1992; U.S. Department of Health and Human Services 1986; Byrd and Clayton 1991; McWhorter et al. 1989; Dayal et al. 1982; Berg et al. 1977; Axtell et al. 1975).

Other studies examined SES as the bridge between race and cancer that explained this association. Using data available through the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) program, which is discussed in Chapters 6 and 9, these studies concluded that SES accounts for what appear to be racial differences in cancer incidence, mortality, and survival. For example, a study on SES and cancer survival (Cella et al. 1991) found that race was not a significant predictor of length of survival, but that income and education, the two bedrock measures of SES in other studies, were. Other research discovered that when cancer rates were adjusted for income or education, the rates for some types of cancer among whites were actually higher than those for African Americans (Boring et al. 1992). Also, a study of white women in Appalachia found rates of cervical cancer, dysplasia, and carcinoma of the uterine cervix similar to those of urban African-American women in the SEER program with similar income and literacy levels (Friedell et al. 1992). Researchers (Bassett and Krieger 1986) who adjusted for social class in addition to age, stage of cancer at time of diagnosis, and histology found greatly reduced differences in breast cancer survival rates between African Americans and whites. Based on the type of cancer, additional research found that SES, measured by poverty level, explained differences in cancer incidence among African Americans and whites (McWhorter et al. 1989).

These studies, as well as more recent findings, suggest that the observed racial differences in cancer incidence, mortality, and survival are explained, to a large extent, by the differences of SES between whites and African Americans and other ethnic and racial minorities (Freeman 1989; Kaplan et al. 1987; Mansfield 1992; Cella et al. 1991; McWhorter et al. 1989; Baquet et al. 1991; American Cancer Society 1986; Boring et al. 1992; U.S. Department of Health and Human Services 1986; Bassett and Krieger 1986; Dayal et al. 1982; Jones 1989). These studies underscore that much of the excess burden of cancer among African Americans and other groups is attributable to SES factors. The American Cancer Society, after reviewing these studies, concluded that members of different racial and ethnic groups with the same SES have almost the same incidence and mortality rates (Freeman 1989). Thus, much of what we know about SES and race comes as the offshoot of studies of race and cancer.

The Effect of SES on Cancer

Although most explanations of higher cancer rates and risks involve low SES, not all do. At least one kind of cancer is likely to occur at earlier ages and exhibits a strikingly different relationship to SES. Malignant melanoma of the skin increased in incidence among Americans age 20 to 44 by 39 percent from 1973-1977 to 1983-1987 (Doll 1991, p. 682). However, unlike the more usual inverse relationship between SES and illness, the incidence of malignant melanoma increases directly with higher SES. Most studies show a decreased incidence of cancer and other illnesses among people with college educations, high income, and white-collar jobs. SES seems

to affect the incidence of malignant melanoma by providing more leisure time to members of higher SES groups; leisure suntanning or intermittent episodes of sunburn increase the risk for malignant melanoma and are more likely to occur among people with the financial means to have and use their leisure to tan or burn (Harris 1989, pp. 174-176).

Breast cancer also illustrates how complicated the relationship between SES and cancer can be. The incidence of breast cancer increases with higher SES, again contrary to what we might expect from other studies of SES and illness and studies of SES and most other cancers. On the other hand, the length of disease-free intervals and the length of survival time from breast cancer increase with SES, as studies would lead us to expect.

One explanation for the different directions of the relationship between SES and breast cancer incidence, survival, and mortality involves reproductive history and access to cancer detection and treatment. The risk of breast cancer for women who have their first full-term pregnancy before age 22 is about one-third that of women who have their first full-term pregnancy after age 30. This may be because earlier first pregnancies reduce the number of estrogen receptors that are associated with a lower level of malignancy in breast cancers and a favorable response to certain types of therapy. Women of lower SES, on average, become pregnant for the first time at earlier ages than women of higher SES. This may explain the lower incidence of breast cancer among women with lower SES. Women of higher SES are more likely to use cancer detection and seek care for symptoms of breast cancer earlier than women of lower SES. Thus, women of higher SES have a higher incidence of breast cancer. However, because of access to care and use of preventive services, they have a higher portion of localized breast cancers than women of lower SES. Early detection and the localized nature of the cancer contribute to longer disease-free intervals and survival among women with higher SES (Harris 1989, pp. 168-172).

The direct relationship between SES and the incidence of breast cancer and malignant melanoma represents a modest qualification of the dominant findings of an inverse relationship between SES and cancer in most studies. The American Cancer Society, in 1986, reviewed the major studies on the link between SES and the risk for cancer. It reported:

- ▶ All studies but one showed survival rate differences among SES groups, with patients of lower SES having reduced survival rates.
- ▶ All studies that showed survival rate differences among SES groups found these differences to persist when adjustments were made for stage at diagnosis.
- ▶ One study found differences among SES groups when controlling for treatment effects.
- ▶ Survival rate differences among SES groups were present across all time periods. The differences between survival rates in the 1940s and the 1960s changed little.
- ▶ Differences in 5-year survival rates between high- and low-SES groups ranged from 6 to 23 percent depending on the site and stage of the cancer.
- ▶ Differences in survival rates among SES groups were greatest for cancers with higher 5-year survival rates overall.
- ▶ Differences among SES groups were apparent as early as a year following diagnosis (Freeman 1989).

The *Report of the Secretary's Task Force on Black and Minority Health* (U.S. Department of Health and Human Services 1986) also concluded that SES is one of the primary factors related to cancer survival. Patients' survival rate was worse for poor patients than for nonindigent patients when the same type of cancer was compared. In 1989, the American Cancer Society conducted hearings across the country to gather firsthand accounts about

cancer and poor people. Based on the hearings, the American Cancer Society came to the following conclusions.

- Poor people endure greater pain and suffering from cancer than other Americans.
- Poor people and their families must make extraordinary personal sacrifices to obtain and pay for care.
- Poor people face substantial obstacles in obtaining and using health insurance and often do not seek care if they cannot pay for it (American Cancer Society 1989, p. 2).

As one woman from rural Appalachia testified in these hearings,

> *To go to the doctor is $50. To get a mammogram is $100 because it's on sale this month. ...To get it read is another $50 to $100, and then my doctor said I need a biopsy if it's suspicious for cancer. I don't have any money. If I quit my job and wait until welfare approves me so I can get a medical card, it's going to be months. Meanwhile, how do I feed my children? (American Cancer Society 1989, p. 21)*

SES and Cancer Studies

Like the explanations of SES and health in general, explanations of the links between SES and cancer fall into several categories. Some focus on the "host factor": characteristics such as age, gender, and genetic susceptibility that can increase an individual's risk of developing certain cancers. One explanation suggests that SES itself is a host factor because stress associated with poverty may impair the immune defense system and enhance the progression of preexisting tumors (Harris 1989, p. 181-185). At the very least, this explanation reminds us of the interaction of SES factors among themselves and the effects of that interaction for risk of cancer.

Other explanations of the relationship between SES and cancer stress historical factors. For example, the history of racial discrimination—including 250 years of slavery and 100 years of legalized segregation—against African Americans has negatively affected their SES status and continues to affect their health (Byrd and Clayton 1991). Racial segregation of schools until 1954 affected the educational levels of older African Americans and, in turn, affected their cancer-related knowledge. A history of culturally insensitive and discriminatory behavior on the part of health care providers has adversely affected health-care-seeking behaviors. These historically influenced health practices may be reflected in statistics showing that African Americans do not receive enough early, routine, and preventive care for cancer and other illnesses (U.S. Department of Health and Human Services 1991, p. 33).

The third and most common explanation of the relationship between SES and cancer treats poverty as proxy for other aspects of living, including lack of education, unemployment, substandard housing, poor nutrition, risk-promoting lifestyles and behavior, and reduced access to health (Freeman 1989). These explanations frequently single out education as a strong predictor of cancer incidence and survival (Pamies and Woodard 1992; Cella et al. 1991; Dayal et al. 1982). Education increases the knowledge and practice of preventive activities such as a healthful diet, abstinence from tobacco, the warning signs of cancer, screening guidelines and techniques of self-examination, and preventing exposure to cancer-causing agents. Education thus reduces the risk of a person's developing cancer and increases the chances of survival if cancer is found.

Conversely, those with less education typically engage in more high-risk behavior, such as using tobacco and alcohol, and are less likely to be aware of preventive measures or important symptoms of cancer. Those with less education may be more likely to be employed in blue-collar or industrial positions in which people are exposed to more carcinogens, such as smoke, asbestos, and

other cancer-causing chemicals in the work environment (Rothenberg et al. 1987; Mansfield 1992; Kaplan et al. 1987; Haan et al. 1987). Furthermore, people with limited education are often unaware of the importance and availability of cancer screening. Preoccupied with the struggles of daily living—demands and resources, such as putting food on the table or keeping a roof over their heads—people who are economically disadvantaged set aside what they consider less important or less immediate tasks like developing a long-term health consciousness (Dayal et al. 1982; Freeman 1989; Pamies and Woodard 1992).

Overall, these explanations suggest that SES affects cancer incidence, mortality, and survival through specific but interrelated factors such as access to health services, nutritional status, immune status and function, education level, living standard, income, social support system, overall health awareness, lifestyle, and knowledge about cancer symptoms, treatment, and prevention (Freeman 1989, 1991; Pamies and Woodard 1992; Cella et al. 1991; Loehrer et al. 1991; Haan et al. 1987). However important any one factor of SES appears, there is no one factor that completely explains the relationship between SES and cancer.

Access to Cancer Services

Because there is no "big bang" explanation of the relationship between illness and socioeconomic status, there is no single public health approach to the problem. Access to screening and preventive services obviously plays a part in preventing and controlling cancer. However, access is not the complete answer. For example, a study of 10 community health centers in the Appalachian area (Patrick et al. 1988) examined questions of access and rural poverty, an aspect of SES of particular importance to participants in the Appalachia Leadership Initiative on Cancer. The study found that, although providing access to health services in low-income communities did reduce health care utilization differences between SES groups, such access did not reduce health status differences. Low income was still associated with lower health status even when physician visits and hospital stays were the same among all SES groups (Patrick et al. 1988, p. 128).

Other evidence suggests that forms of care, not access alone, do make a difference in outcomes. A comparison of patients in Veteran's Administration (VA) hospitals found that the survival rates of cancer patients were similar for patients of different races and incomes. The study suggested that when everyone is treated the same regardless of race and the costs of care are removed, such as in the VA system, patients of difference races and incomes have similar health outcomes (Page and Kuntz 1980).

The current health gaps among SES groups are likely to increase without efforts to provide better access to health care regardless of the ability to pay. However, increased access to health care is a necessary but not sufficient condition to improve the health status of low-SES groups. Increasing access will be more effective if public health officials acknowledge the interface of the culture of medicine and SES (Patrick et al. 1988, pp. 130-133). Most explanations of the relationship between health status and SES examine the culture and characteristics of low-SES groups. Few studies examine the culture of medicine. The studies that do, however, suggest a need for cultural change in medicine. For example, an American Cancer Society survey of cancer and SES found that current medical education programs are culturally insensitive and irrelevant to many poor people (American Cancer Society 1989). The problem of health care access for people with low SES requires not only more services but also changes in the services and providers that poor people find when they seek health care.

Community-Oriented Primary Care

The establishment of community health centers has reduced the gap in access and utilization for the rural poor, including those in Appalachia. More is needed, and in some community health centers in Appalachia and the nation we find efforts to reduce the health outcome gap. These efforts, grouped together and called community-oriented primary care (COPC), reunite the traditions of public health and individual clinical health services. It is a community-responsive practice that assumes a larger-than-ordinary responsibility for safeguarding the health of a community and follows through on this responsibility by taking action beyond the traditional mode of treating complaints and problems of patients on an individual basis (Nutting 1987, p. xvi).

Community-oriented primary care is not a magic talisman to cure all problems related to SES and illness. However, COPC is clearly related to several aspects of ALIC. Its emphasis on integrating resources is one part of the horizontal integration that Chapter 8 emphasizes in its discussion of community coalitions. Its emphasis on bridging different cultures is one part of the differences explored in the chapters in Section I.

COPC also serves to remind us that ALIC is part of the development of a broad array of disease prevention and health promotion activities. This development is part of measures to detect illness, such as cancer, as soon as possible after it has developed and even before its symptoms are apparent. Extending access to low-income groups is an important part of early detection. ALIC attempts to make more available the means of early detection such as screenings and checkups. Much has been done. Much remains to be done.

ALIC is a venture in cancer prevention as well as early detection. Prevention emphasizes what people can do for themselves to avoid illness and promote health. Reducing behaviors that present cancer risks, such as tobacco use, heavy alcohol consumption, poor nutrition, and excessive exposure to the sun, is part of prevention. ALIC addresses these behaviors. Some of these behaviors are voluntary; however, they also are related to conditions of demands and resources, environmental quality, and the interaction of SES factors. Among low-SES groups, therefore, prevention needs to address the involuntary risks for cancer and other health problems associated with poverty or rural residence, as discussed in Chapter 5. The possible conflict among coalition members in sorting out emphases on prevention and early detection as well as voluntary and involuntary behaviors as they relate to SES is a focus of Chapter 8.

Disease Prevention, SES, and ALIC

In 1983, the National Cancer Institute established the goal of reducing cancer mortality by 50 percent by the year 2000. Vital to the achievement of this goal is the narrowing or elimination of the gap in cancer incidence, mortality, and survival among Americans of different SES levels, including those who are socioeconomically disadvantaged. To reduce this disparity significantly by the turn of the century, leaders of the cancer-reduction movement called for effective public education and awareness campaigns targeted to low-income groups along with strong advocacy for legislative changes to provide for better access to and distribution of cancer information, screening, diagnosis, and treatment (Freeman 1989).

Health interventions by community-based coalitions are good mechanisms for meeting many of these goals and challenges. The coalitions can provide and foster the networks and cooperation needed to reach those at high risk of cancer. The challenge rightfully falls to coalitions because it can be met only with the local knowledge, cooperation, dedication, and commitment of an array of civic leaders, medical care providers, and social service agencies.

Several studies of the relationship between SES and health specifically examine recom-

mendations to direct coalition efforts to improve the health of low-SES groups (Amler and Dull 1987). The American Cancer Society (1989, pp. 9-10) developed 10 broad principles of intervention related specifically to the cancer gap and SES.

1. Ensure that cancer prevention, detection, treatment, and rehabilitation services are accessible and available to all who need them, regardless of their ability to pay.

2. Improve cancer prevention and early detection among poor Americans to eliminate unnecessary pain, suffering, and death.

3 Undertake aggressive educational efforts to counteract fatalism, overcome fears, and enable poor people to reduce cancer risk.

4. Improve and expand public and private assistance, including health insurance, for the poor.

5. Develop cancer education materials and outreach programs that are culturally sensitive, understandable, and relevant to poor people.

6. Establish patient advocate and referral services to help poor patients navigate the health system and manage personal problems that result from cancer treatment.

7. Involve community organizations serving poor people and the people themselves in cancer education and patient advocacy programs.

8. Train health care providers to be sensitive to the needs of poor patients and to serve their needs more effectively.

9. Expand the availability of and accessibility to health services for poor people of rural areas, which are now underserved.

10. Conduct research to further document the scope of the gaps of cancer and health services and identify effective interventions.

Patient advocates, patient empowerment, and provider training all are necessary to make improved access effective. The objectives of *Healthy People 2000* also combine increased access to screening and detection with training for health providers, improved educational services for at-risk groups, and lower levels of high-risk behaviors (U.S. Department of Health and Human Services 1991, pp. 43-51).

Other recommendations for effective interventions are implied in a study of successful social interventions to prevent "rotten outcomes" such as excess and unnecessary cancer (Schorr 1988, pp. 256-259). Schorr examined programs to prevent teenage pregnancy, developmental delays in children, problem pregnancies, infant mortality, and other disease and illness conditions strongly associated with SES. Her examination led to the description of several characteristics of successful interventions:

- A broad spectrum of services related to the condition to be addressed, which acknowledges the condition as a symptom of a complicated interrelation of a host of factors;
- Making traditional professional and bureaucratic boundaries permeable so that agencies and personnel within them have the means and authority to do what is necessary to address a problem;
- Flexibility within a program and approaches to devising the set of services and interventions appropriate to a particular person and permitting that person to choose among them;
- Contextual understanding of the problem;
- Care and respect for those served and trust in those serving;
- Coherent and easy-to-use services;
- Adapting or circumventing traditional bureaucratic and professional limitations within a program when necessary in light of the needs of those to be served; and
- New self-defined, more effective roles for professionals.

Conclusion

Several health interventions in Appalachia have the attributes recommended for effective programs to redress the relationship of low

SES and poor health. The health centers operated by the United Mine Workers of America in the 1950s were forerunners of the community health centers of the 1960s that Schorr (1988) lists among effective interventions. Appalachia has more than its share of model community health centers. Primary care providers have been leaders in community-oriented primary care. Most recently, Appalachia was the site of the development of community-based maternal and infant health interventions (Clinton 1992), renewing a tradition of the Frontier Nurses.

In undertaking ALIC, program staff, community leaders, and coalition participants renew a wealth of health innovations and interventions to improve the health of low-income groups. These efforts make us aware of the complex relationship between SES and cancer as well as the difficulty of finding an effective mechanism to narrow the cancer gap among SES groups. ALIC begins with this history and awareness. It begins also with an assurance that community-based coalitions offer one promising path to improve health despite the disparities in SES.

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CHAPTER 7

Action Steps

1. Assess current outreach and preventive services for their ability to reach people in low-socioeconomic groups at high risk of developing cancer.

2. Involve low-income people in local coalitions to develop effective public education and awareness campaigns, advocate for legislative changes for better distribution of cancer information and prevention programs, and increase access to cancer screening, diagnosis, and treatment services.

3. Identify and address local factors of socioeconomic status (SES) that contribute to poor health and the increased risk of cancer, including housing, income, occupation, diet, education, personal relationships and social support systems, access to care, and the environment.

4. Improve cancer prevention among low-income area residents to prevent the increase of cancer incidence.

5. Educate local health care providers about the latest screening technologies and treatment standards.

6. Evaluate the sensitivity of health care institutions and providers to the needs of people in poverty and their ability to meet these needs.

7. Develop educational materials and outreach programs that are culturally sensitive to Appalachian people, understandable, and relevant to people of low SES.

8. Include programs that promote self-efficacy among people of low-socioeconomic groups and lifestyle changes that reduce their risk of cancer.

9. Work with schools and other community institutions to develop cancer prevention education programs for children and adolescents growing up in low-income communities and environments.

10. Ensure that cancer education and prevention programs, interventions, and other services:

—Address conditions characteristic of the local region;

—Acknowledge the complicated relationship among cancer-causing factors;

—Are flexible in design and approach so that they can be altered to meet the needs of those being served;

—Have a contextual understanding of cancer risk; and

—Foster care and respect for cancer patients and trust in health care providers.

CHAPTER 8

Community Coalition Theory and Rural Practice

Paul W. Speer and David M. Chavis

Coalitions comprise a method whereby numerous organizations can generate the power capable of influencing broad policies and resource decisions. Organizational power of this magnitude is necessary to change the conditions of our social infrastructure and the effects of these conditions on families and communities. A key component of the Appalachia Leadership Initiative on Cancer (ALIC) is the development of community coalitions. ALIC focuses on cultivating cancer prevention and control efforts in communities within the Appalachian region that are affected negatively by social and economic forces.

This chapter highlights theory and research about community coalitions that can provide important information for ALIC projects. Types of coalitions, formation processes of coalitions, and maintenance of coalitions are described to support collective efforts to control cancer in the Appalachian region.

Coalitions Defined

By the 1980s, coalitions had become commonplace in American communities (Boyte 1980; Miller and Tomaskovic-Devey 1983; Weisner 1983). Although reasons for the emergence of community coalitions vary, they often are tied to the shortage of social resources available to deal with the needs of communities. This lack of social resources is linked to reductions in social spending, particularly at the federal level. In addition, coalitions have increased as individuals and groups recognize that many community problems have roots in large, macrolevel forces that affect life at the municipal and community level.

Coalitions have been defined as temporary, means-oriented alliances among individuals and groups, each of which have differing goals (Gamson 1961). Coalition is derived from the Latin word *coalescere*, which means "to grow together." Although the origin of the term suggests a long-term process, many coalitions are temporary; nevertheless, coalitions and coalition theory increasingly focus on growth or development within coalitions (Florin et al., in press).

Coalitions hold promise for producing social change because they can link enough community organizations, social service agencies, and community institutions to produce the necessary power for change. Individuals must work collectively to facilitate change in social structures (Kidder and Fine 1986). People come together to form special groups called "mediating structures" as a link to the larger society (Berger and Neuhaus 1977). Community coalitions with the closest ties to people are composed of these mediating structures, which include neighborhoods, families, churches, voluntary associations, and the workplace, among others. Mediating structures are people-sized—that is, they are small

enough to reflect the values and realities of individual life, yet large enough to empower individuals and influence social change

Historically, social change efforts focused on the point of production. The union movements of the 1930s and 1940s represented conflict between labor and management. Struggles existed over wages and working conditions, among other issues. Following the rise of social consciousness that occurred in the 1960s and 1970s, collective change efforts have been directed at the point of consumption (Perlman 1976); have targeted social service or economic endpoints; and have been brought about by groups, frequently community groups and other mediating structures, pressing for accountability from state or corporate interests. In these efforts, individuals act collectively through mediating structures for the purpose of creating social change.

Over the past 25 years, the growth of community organizations has been described as a movement (Boyte 1979, 1980; Giloth 1985; Kotler 1979; Perlman 1976; Schwartz 1979). Community organizations, as mediating structures, offer a context in which individuals can have some influence on broader social structures. However, the magnitude of forces that converge to create community problems are often so great that singular community organizations may not have a significant impact. For this reason, community organizations are joining together increasingly to form coalitions with other community organizations to address issues affecting families and communities.

Community coalitions face unique challenges by attempting to incorporate the grassroots of a community and the diversity of interests therein. Particularly challenging is an acceptance of this diversity within a coalition framework. Research about the models, processes, and strategies of forming community coalitions presents important considera-

tions for those Appalachian communities developing community coalitions focused at cancer prevention.

Community Coalitions

A community coalition is a formal alliance of organizations and institutions from within a community (e.g., town, county, city) based on a clearly expressed common purpose, need, and issue. The organizations that comprise a community coalition range from local governmental agencies to businesses to volunteer and nonprofit organizations. Local government agencies frequently include police and law enforcement agencies, housing authorities, courts, educational institutions, and others. Business organizations can include banks, chambers of commerce, large corporate interests, and local merchants. Volunteer and nonprofit organizations often include neighborhood organizations, tenant groups, parent-teacher organizations, churches and other religious groups, nonprofit hospitals, and fraternal and service clubs.

The central role of local voluntary organizations is what makes community coalitions unique. Local voluntary organizations are important because they have the greatest access to a broad range of community residents and more often represent their values and issues. Voluntary organizations can reach deeply into the community by involving the breadth and diversity of its people. Volunteer or grassroots organizations generally are (1) geographically based; (2) volunteer-driven, drawing resources primarily from the time, skills, and energy of members; (3) initiated locally by residents responding to local conditions; (4) organized on a human scale where decisions are made face to face and operations are informal; (5) focused on problemsolving, emphasizing the importance of getting specific tasks accomplished; and (6) designed to be multipurpose, flexible, and able to address a variety of issues simultaneously and to adjust strategies when necessary (Florin et al. 1992).

Although volunteer organizations share several organizational characteristics, they differ in important ways. The first distinction among organizations centers on the differing issues they address (e.g., youth, the environment, tax issues); a second important difference is in the organizational base of these groups. Kahn (1982) identifies four organizational bases from which volunteer groups emerge: union (based in the workplace), community (based on location), constituency (based on individual characteristics such as age or ethnicity), and issue organizing (based on specific issues such as the environment or taxes). Institution-based organizing is based on work with organizations that were formed for other purposes but that have the organizational structure and group cohesion needed to sustain a stable and practical organizing base, such as churches and schools (Speer 1992). Volunteer organizations use different methodologies to achieve their objectives. The most commonly cited methods of community groups include social planning, social action, community development, civic agency, and electoral and pressure group approaches (Boyte 1980; Perlman 1976, 1979; Rubin and Rubin 1986; Wandersman 1984).

One difficulty facing community coalitions is that member organizations traditionally have segregated themselves into two groups: volunteer advocacy-oriented organizations and nonvolunteer service-oriented organizations (Cunningham and Kotler 1983; Weisner 1983). Despite their connectedness to and understanding of community issues, volunteer organizations are difficult to include in coalitions because their organizational development frequently is unlike a coalition's other member organizations. For example, establishing voluntary organizations usually have fewer resources than nonprofit organizations, businesses, and governmental agencies.

Another challenge to community coalitions is that coalition activities may deplete the resources needed to maintain member organi-

zations, particularly voluntary organizations. Coalitions have requirements for membership, such as meeting attendance and task performance. These requirements detract from the already limited organizational capacity of voluntary organizations (O'Sullivan 1977). The resources of voluntary organizations are the time, skills, and energy of community members. The circumstances of nonvolunteer organizations are very different. For example, establishing coalition meeting times can be difficult because individuals working with government agencies, nonprofit organizations, and businesses frequently meet during the workday; whereas voluntary organization members usually meet in the evenings.

A great variety of organizations, with different purposes, bases, and methods, exists within communities today; the increasing importance of coalitions stems from the fact that these organizations rarely can achieve social change goals independently. Increasingly, there has been a realization of the social forces that impinge on individual, family, and community life (Bronfenbrenner 1979; Garbarino 1992). Effective health promotion and disease prevention require a comprehensive approach; therefore, a system must be in place to deliver a variety of resources and opportunities to individuals—for example, transportation, education, health services, economic opportunity, social support, public education, and marketing.

Well-planned community coalitions can be exceptionally effective in health promotion and disease prevention efforts by linking voluntary organizations such as community organizations, unions, social and recreational organizations, block clubs, and churches with hospitals, social service agencies, schools, businesses, and governmental agencies. Together, these groups have a greater potential to address environmental and social conditions, can produce a more comprehensive approach, and can provide greater access to community residents. This linkage, if well designed, can lead to increased community ownership and participation in health promotion.

Cancer control coalitions need to address three common problems faced by all community organizations working on health issues (Lipsky and Lounds 1976). First, successful involvement of people through community organizations requires that individuals understand the linkage between their organization's activities and a fundamental issue in people's lives. When people use the health care system infrequently, it is difficult to involve them in health issues. Second, those most affected by health care issues, the elderly and the acutely ill, are least able to participate in community activities. Third, health issues are extremely individualized. Environmental and systemic forces contributing to poor health are more difficult to perceive; therefore, it is more difficult to mobilize broad-based community participation around these issues.

Research about models, formation, and development of coalitions raises important considerations for those Appalachian communities developing coalitions focused on cancer prevention.

Models of Coalition Behavior

Coalition models categorize the types of organizations assembled in a coalition and how those organizations relate to one another. Most community coalitions can be identified with one of two models: a horizontal model, which links professionals from many agencies and services within a community to address problems, and a vertical model, which works with multiple levels, predominantly the grassroots level, within a specific community institution.

The Horizontal Model

Most community coalitions fit the horizontal model, as they are composed of a "horizontal layer" of the community. The horizontal model of community coalition frequently stresses collaboration among social service

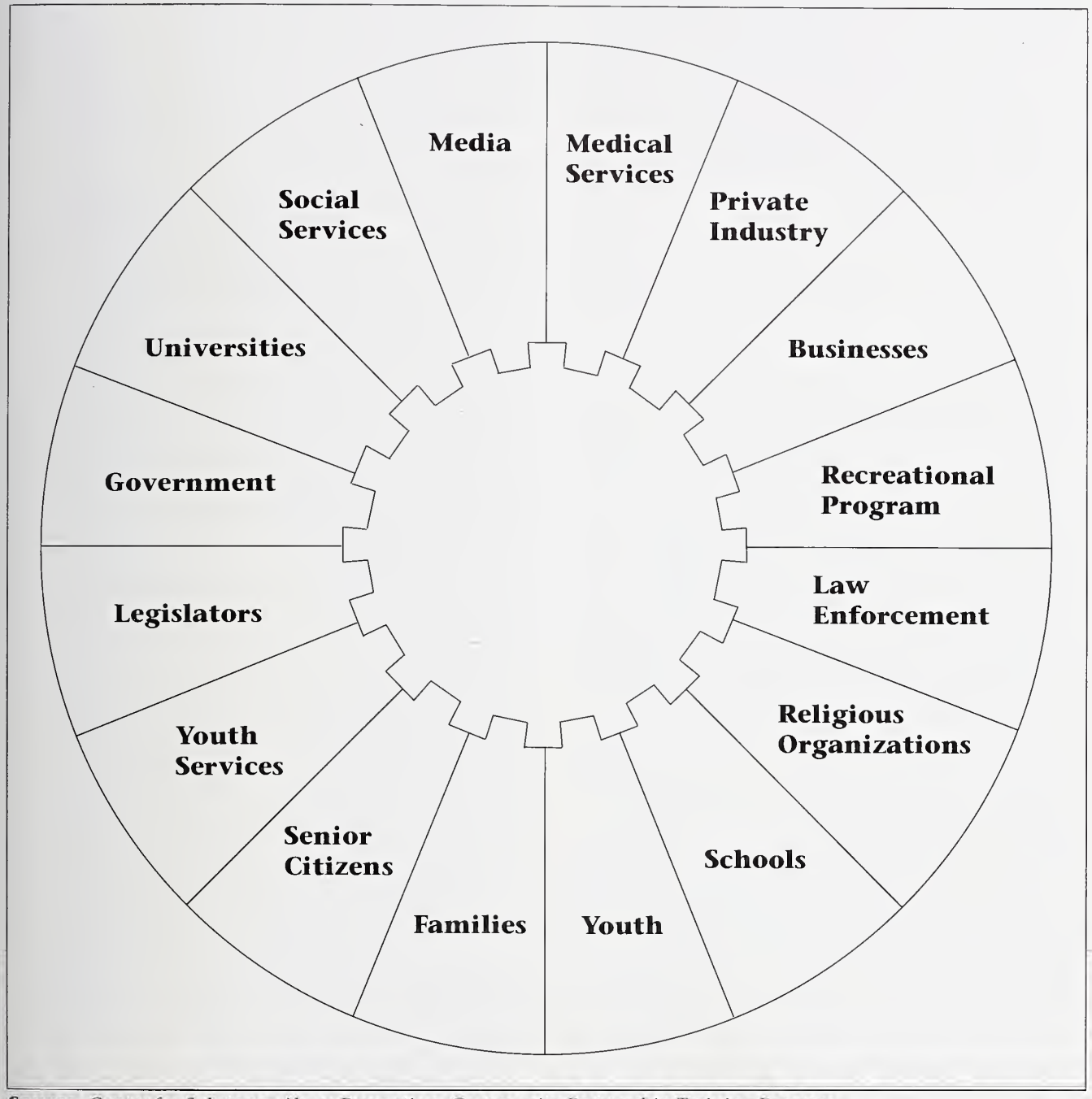
agencies and governmental entities. The strength of horizontal coalitions is that they often draw top-level representation from multiple sectors of the community. The horizontal model is exemplified in many Robert Wood Johnson Fighting Back initiatives and in the Center for Substance Abuse Prevention's (CSAP) Community Partnership Training Program. In these coalition structures, professionals from a spectrum of community institutions and organizations participate. CSAP uses a "community wheel" (Figure 1) to depict the multisector institutions that would ideally be represented in a community coalition. Horizontal coalitions pull professionals and leaders from many community sectors to encourage collaboration, thus facilitating innovative arrangements between participants for specific community issues. One weakness of this model is that those most affected by community problems are not as well represented as is the existing power structure of a community. Horizontal coalitions have several common characteristics: They focus on changing systems; collaboration is stressed at the level of "formal" community leaders; organizational structures comprise issue-based committees; and citizens are enlisted to assist in defining and solving problems (Chavis et al. 1993). In practice, however, citizen participation is very limited in horizontal coalitions. For example, a recent study of 1,650 alcohol and other drug abuse prevention coalitions shows that although 47 percent of the coalitions stated that running programs was among their proudest achievements, only 5 percent placed involving citizens as such an achievement (Rosenbloom et al. 1992). Furthermore, only 35 percent of the coalitions studied reported involving representatives of affected populations in the coalitions.

Horizontal community coalitions are composed of professionals within the community and often "do for" community residents rather than work with these residents. They are not unaware of or insensitive to the needs and desired involvement of community residents, but they are often functionally isolated from these sectors of the community. Community residents often level two criticisms at horizontal coalitions. First, horizontal coalitions usually involve community representatives who do not really represent the community (Lipsky and Lounds 1976). Community residents often perceive their identified representative to be very visible but unrelated to the community. Second, when community residents are given the opportunity to address horizontal coalitions, they feel intimidated by the professional culture of these coalitions and perceive that their perspectives are not really heard (Green 1986).

The Vertical Model

Vertical community coalitions are predominantly focused at the grassroots level. They involve the constituency of an organization or institution with the supportive involvement of the organizational or institutional leaders. Vertical coalitions share several common characteristics: They focus on systems change; leaders are drawn from the grassroots level; the key process in developing the coalition is the cultivation of social bonding among individuals within the organizational or institutional setting; leaders are identified from within each individual organization to represent that organization in the coalition; and formal community leaders are enlisted for problem solution. One example of a vertical coalition is the New Jersey Comer School Development Program. Parents work together to become involved in a school and interact as equal partners with teachers and principals in developing policies and priorities for their children's educational environment (Comer 1980). Similarly, church-based organizing networks—such as the Pacific Institute for Community Organization and the Industrial Areas Foundation—are developing community coalitions drawn largely from churches. Working predominantly with church parishes and

Figure 1. Community wheel



Source: Center for Substance Abuse Prevention, Community Partnership Training Program.

congregations, these vertical coalitions enlist the support of religious leaders within the active denominations.

Vertical coalitions are based in community institutions; existing organizations, usually schools and churches, form the basis of the coalition because their organizational requirements, which are so important for coalitions, are more developed than those of most voluntary organizations. In the case of churches, a coalition can be maintained at multiple levels. Congregation members can work with members of other churches, just as pastors and bishops of different churches can work together; the same is true for schools. The strength of vertical coalitions is that they can tap deeply into the grassroots of a community. By utilizing the organizational structure of a particular institution, they can develop the organizational capacity needed for accessing

power. The weakness of these coalitions is that even when a coalition develops significant power within the community, it is rare that a coalition composed of a single institution (e.g., schools, churches) can develop enough power to address the magnitude of the problems faced by communities.

An Integrated Model

A set of principles has emerged in the literature that addresses how coalitions can operate most effectively within communities. This body of knowledge draws on systems theory to understand how organizations function within their environment (Berrien 1968; Katz and Kahn 1978). The application of systems theory to community coalitions allows an understanding of coalition phenomena in terms of input, throughput, and output. Systems theory suggests that community coalitions receive varied input from the environment, that the input is transformed through the coalition's structures and functions, and that the output then affects the environment. Coalitions must combat a tendency toward entropy or disorder by developing an orderly throughput that produces a homeostatic state for the coalition. A productive throughput requires structural components of a coalition to be linked functionally to ensure stable operation and sufficient resistance to entropic forces. These systemic principles, together with features of both the horizontal and vertical models, have been combined into an integrated model applied in the state of New Jersey (Chavis et al. 1993). The key principles of the integrated model are described below:

► **Multilevel infrastructure:** Communities function at multiple levels, such as the state, county, city or town, neighborhood, and block levels (Hunter and Suttles 1972; Janowitz 1952). However, different levels of community structures often operate independently or without support for the efforts of other levels of these community structures. Different levels have different functions and responsibilities that need to be brought together to coordinate their individual operations. The more community structures can be integrated to address and support the mutual needs of other levels, the more effective the efforts.

► **Programming across the continuum:** To be effective, health promotion and disease prevention initiatives need to be multifaceted and relatively comprehensive (Eriksen et al. 1988). A large number of community institutions will have some role in the issue's resolution. However, these institutions often are isolated and respond to the issue from a singular perspective rather than from one cognizant of how the issue relates to other institutions addressing the problem. Coalitions must involve a broad spectrum of organizations and institutions to cultivate cooperation among institutions to address health issues successfully.

► **Family- and community-driven strategic planning:** Based on the premise that all community institutions exist primarily to enhance the quality of life for individuals within the community, collaborative planning is a formal process used by institutions to achieve this and other goals. Involving institutions in community coalitions can provide a forum capable of encouraging collaborative strategic planning that responds to community needs by making initiatives accountable to the needs and aspirations of families and neighborhoods.

The integrated model, based on these principles, also seeks to involve key aspects of both the horizontal and vertical models. The integrated model involves representatives of businesses, nonprofit organizations, and local government as well as members of grassroots organizations in the coalition. Traditionally, these two aspects of the community have been alienated from each other. The integrated model utilizes an organizational structure that acknowledges this traditional fissure. This

acknowledgment serves not to legitimize differences but to address the organizational differences between formal structures (government and social service agencies) and voluntary organizations. Specifically, the integrated model utilizes two overarching strategies: parallel process and the enabling system. Because many voluntary grassroots organizations face such complex organizational issues, they are developed as a coalition separately from the service agencies, local government, and businesses. Simultaneously, these formal or professional organizations also are developed as a coalition. This concurrent development represents parallel processes for these differing levels of the coalition. Parallel processes work to strengthen the interorganizational capacity of both voluntary organizations and professional organizations until each sector of the coalition can contribute positively to the coalition effort. Parallel processes explicitly recognize the differing roles of staff, community leaders, and coalition members, but trainings are developed to respond to the roles and responsibilities of each person in the coalition process. The enabling system is a systematic support strategy used to maintain and develop large numbers of community initiatives. The enabling system supports the parallel processes and overall community coalition development by providing consultation, training, network development, evaluation, and other services to support these efforts (Chavis et al. 1992).

The integrated model seeks to address weaknesses in previous approaches by building on the strengths of each approach. The integrated model is time-intensive; however, because this model is structured to develop the skills of both sets of organizations, both sets of stakeholders have respect for what each can bring to the table when integration takes place. Whereas traditional vertical coalition models expend much energy in getting community institutional representatives to address voluntary organization members, the structure of the integrated model brings these different levels of the community together. Similarly, the horizontal model spends a great deal of energy in recruiting community residents to participate once programs and strategies are identified. The integrated approach to community coalitions, in contrast, allows more energy to be spent in addressing coalition purposes and goals rather than in maintaining the internal coalition.

Coalition Formation

Many issues must be considered in coalition formation, and the literature provides important information on this topic. Coalitions are generally formed around an issue or set of issues that are related in some meaningful way to a group of individuals. The prime motivation for developing a coalition is generally some impetus in the environment (D'Aunno and Zuckerman 1987; Gray 1987). Although coalition members may have very different motivations, they must have some organizational interest in joining the coalition.

Recruitment

Identifying potential participants requires a recruitment strategy focused on how the goals of a particular coalition affect possible coalition members. A sponsoring committee or small group frequently will make initial contacts with organizations in the community to test the interest in participating in a particular coalition. Those building the coalition must be able to assess the interests of community organizations and agencies visited and how their interests relate to the coalition (Kahn 1982). One pitfall in the recruitment process is the belief that coalition members must have similar goals and philosophies to work together. This is not necessarily the case; very different groups may work together if it is in their organizational interest. Indeed, some very similar organizations may have greater difficulty working together in a coalition because each perceives the other as a

threat to its organizational turf (Mizrahi and Rosenthal 1992). Another caution in the formation phase of coalition development is the overlap in organizational and coalition goals. Agencies and organizations that perceive coalition activities as duplicating their own existing programs (and thus competing with them) not only will withdraw active support but also may undermine the coalition formation process (Lindsay and Edwards 1988). In recruitment conversations with leaders from community organizations and agencies, sponsors must articulate the unique needs a coalition could address and how membership in such a coalition is advantageous to each particular organization or agency.

In addition, individuals recruited to participate in the coalition must be good leaders within the organizations they represent. Particularly in relation to voluntary organizations, the selection process that identifies community representatives for a coalition often selects individuals who speak the loudest and get attention, without regard to whether they represent the community. In contrast, representatives who demonstrate leadership skills important for successful coalition development are those who have a constituency; they know the stories of people who live in the community and can provide concrete examples of how an issue affects many families in the area. This characteristic ensures accountability between the coalition and community members, producing more support for coalition efforts. When coalition representatives lack a constituency, alienation frequently occurs between the coalition and community residents.

Organizations and Coalitions

One critical feature of coalitions, not often explicitly considered in the coalition literature, is the difference between an organization and a coalition. An organization has several important characteristics: a history, mechanisms for conducting business and making decisions, a cohesion or connectedness among members, and a pattern or cycle through which all these features unfold and make the organization unique. A coalition comprises many organizations. This distinction is important because difficulty often arises in community coalitions when a coalition accepts entities for membership that are not truly fully operating organizations. One key to success is to build the coalition with working organizations. Unless the organizational units composing the coalition are developed and operational, the coalition will spend a great deal of time focused on internally maintaining the coalition rather than on developing or acting on the issues around which it was formed.

The distinction between organizations and coalitions is especially critical to the formation of community coalitions. Although community organizations, which are the basic building blocks of coalitions, may themselves be successful, the skills and techniques that make these groups strong do not necessarily do the same for a coalition (Mizrahi and Rosenthal 1992). The organizational health of many grassroots organizations is precarious at best. For example, voluntary organizations with long histories often are actually dominated by one or two people. Although a voluntary organization may be viewed as successful, deficiencies in organizational depth and development may become manifest when it joins a coalition. The tasks and activities required by membership in the coalition may detract from an organization's independent activities. Such internal organizational problems clearly detract from the coalition's success. During the process of forming a coalition, attention must be given to the organizational health and capacity of potential members. Particularly with voluntary organizations, problems will arise in the course of coalition involvement. Sensitivity to these issues and awareness of potential problems should be considered in the formation of community coalitions.

In addition, community coalitions are sometimes in danger of being dominated by one or two powerful organizations. This is particularly true when a coalition includes a member organization that is dominant in the community. A representative from a large business entity, a particularly eminent elected official, or a lead agency with a large budget can impose a perspective on the coalition that essentially controls the coalition agenda. These situations are especially difficult when the dominant institution has leverage over other organizations in the coalition. In the formation stage, sponsors must remain sensitive to the fact that coalitions sometimes evolve so that this type of power dynamic emerges. The relative power of member organizations should be considered carefully when forming a coalition. Sponsors must assess the costs and benefits of invitations to disproportionately powerful organizations.

Leadership

Identifying good leadership when forming a community coalition is both difficult and important. The goal of identifying coalition leadership is to find individuals who can set aside their immediate organizational interests for the good of the coalition. Leaders must be sensitive to the dynamics that can emerge in community coalitions, such as power distributions, turf issues, and conflicts between organizational and coalition interests. Coalitions need leaders who can be sensitive to these problems yet articulate the coalition's vision and potential for success when member organizations work together.

Roles and Responsibilities

Clarity of purpose is especially key for community coalitions to develop the trust and cooperation that is needed to address change issues effectively (Katz and Kahn 1978). A mission statement and specific objectives and tasks for reaching those objectives can be very important. Limiting the number of objectives and activities, particularly at the outset of coalition formation, is also important. It is often helpful to have successes early in a coalition so that member organizations remain hopeful and invested.

Role clarification is important in community coalitions that include members from both the professional and the grassroots levels of a community. When responsibilities and expectations are not explicit, professional dominance often emerges. As discussed earlier in this chapter, community residents in many coalition settings report feeling intimidated by the professional atmosphere; when residents do contribute to the process, they often feel they are not really heard. If roles and responsibilities are clarified in the formation stage of coalition development, this problem can be overcome early and the expectation that everyone should contribute to the coalition will be better accepted.

Coalition Maintenance

There is some question regarding when a coalition transforms from the formation stage to the maintenance stage. It is clear that maintenance can occur no sooner than the point at which member organizations come together to assess costs and benefits of membership (Roberts-DeGennaro 1986). At the other extreme, formation of a coalition may be motivated by an external source such as a governmental requirement for funding. In this case, maintenance may be considered to start after funding has ceased.

Coalition maintenance is the biggest challenge for coalitions. Particularly as coalitions respond to changes in their environment, their internal structures must reflect these new changes. Although it is relatively easy for a coalition to recognize and acknowledge changing circumstances, taking steps to respond to changes, such as altering internal processes and relationships among coalition members, is a daunting challenge.

Coalition Management

Once a coalition has been formed, managing it may appear relatively easy. Management will be necessary to react to problems and difficulties that inevitably arise. However, management also must consider proactively the assumptions by which the coalition was formed to see whether they are still applicable given changing environmental circumstances. This process is key to coalition maintenance. Benson and colleagues (1973) have identified four factors associated with coalition maintenance: (1) domain consensus, focusing on the scope of the coalition; (2) ideological consensus, addressing the methods of achieving goals; (3) work coordination, representing the activities and production of the coalition; and (4) evaluation, representing the shared judgments on the coalition's work quality. These factors must be balanced in the coalition maintenance stage. Although each factor will have been addressed during coalition formation, each aspect of the coalition must be reviewed continually to adjust to changing circumstances.

Dynamic Tensions

Mizrahi and Rosenthal (1992) have identified four dynamic tensions that must be balanced to maintain coalitions. First, mixed loyalties address the dual commitment of individual coalition participants—to the coalition and to the organization they represent. This tension can be especially difficult for member organizations that have organizational goals that are similar to those of the coalition, which may result in feelings of competition for scarce resources. Second, autonomy versus accountability represents the need for coalitions to take independent action on issues requiring immediate action. This independence may create problems with member organizations that believe the coalition is no longer accountable. Third, means versus model addresses the purpose of the coalition, whether it is to achieve a social change goal—a means—or to achieve interorganizational relations and coordination—a model. The longer a coalition exists, the more likely it is to be viewed as a model. Fourth, the tension between diversity and unity focuses on the need for coalitions to balance their sources of strength. Diversity stems from the broad base of support and participation that coalitions harness, and unity is represented in the power that comes from organizations working together in a focused manner.

Coalition Structuring

Gray (1987) describes a process model for understanding the three stages through which a coalition evolves: problem setting, direction setting, and structuring. The structuring phase focuses on creating long-term structures for the coalition's collaborative activities. Structuring is the key stage of coalition maintenance, and success in this phase is based on several principles. First, interdependence works to maintain a coalition. As coalition members recognize their dependence on each other, communication is increased, which serves to hold the coalition together. Second, redistribution of power occurs during the structuring phase of coalition maintenance. Although it is best if power is widely dispersed during the formation state of coalition development, this is not the case in the maintenance stage. Power is redistributed to realign both power and responsibility within the coalition. The rationale of power redistribution should be based on the long-term goals of the coalition and must be sensitive to issues of trust and benefits to coalition members who are giving up power (Gray 1987). Third, geographic proximity is identified as a principle influencing the structuring phase of coalition maintenance. Whereas geographic dispersion increases the cost of collaboration, geographic proximity enhances and supports the maintenance of coalitions.

Coalition Benefits

To maintain a coalition at any point, the benefits of membership must outweigh, or at least equal, the costs (Prestby et al. 1990). The benefits that organizations may receive from joining a coalition are often intangible, and this is particularly the case for organizations working for social policy changes. Nevertheless, benefits exist, such as media and public attention, perceptions of power and influence, and growth in an organization's membership and budget (Miller 1983).

The division of benefits can be very important. Methods for determining which organizations receive the credit for organizational activities should be explicit in coalitions. However, the process of explicitly addressing how credit will be divided can be a source of tension. Coalitions require trust and cooperation among member organizations. Too much attention to dividing benefits prior to performing the work can destabilize a cooperative atmosphere and detract from actual task performance. Ignoring potential benefits also can feed an unhealthy skepticism and destroy trust. Solutions to this problem require distributing benefits broadly, particularly early in the coalition's development. As time passes and successful efforts mount, both the need to distribute benefits and the trust to discuss them more openly will be possible.

Another potential problem related to benefit distribution is the separation of coalition activities from member organization activities. This is especially true for member organizations that have very similar goals to the coalition. Clear articulation of entities responsible for activities should be made, particularly public recognition of success.

Considerations for Participatory Coalitions

Coalitions are very complex structures, but they are increasingly necessary when considering the social problems faced by communities today. Strong coalition structures are necessary to develop successful community coalitions to control cancer in Appalachia.

Participation

Broad participation by citizens and their major institutions is important for cancer prevention and control efforts. Because those individuals who are most at risk for developing cancer are often those most difficult to reach, mechanisms for reaching these populations are of critical importance. For this reason, voluntary organizations (e.g., churches, unions, schools, 4-H clubs, workplaces) must be involved in cancer control coalitions.

Voluntary organizations provide the best mechanism for reaching at-risk populations; however, only a small proportion of this target group is directly reached by these kinds of organizations. One factor that increases an individual's risk in the first place is not being connected to others in the community (Hawkins and Catalano 1992). Nonetheless, voluntary organizations can indirectly access this at-risk target population. This is because many individuals who participate in churches, parent-teacher organizations, block clubs, and the like do come into contact with those most isolated from the community. In this way, through indirect interpersonal contact, voluntary organizations reach out to the breadth and depth of a community. This strength of grassroots organizations makes them essential to cancer control coalitions.

Although interpersonal contact can be made, involvement of the at-risk population is by no means assured. Two factors optimize the potential for an individual's involvement in coalitions: interpersonal relationships and motivation. First, if a member of the voluntary organization, or any member of the community, has a relationship with someone, that relationship can effect participatory behavior. Second, individual motivation must be based on something of value to the potential participant. People act out of their own interests; immediate, concrete, specific needs are the

motivation for action. Just as voluntary organizations are successful to the extent that they address issues of interest to community members, health care coalitions must do the same. Community coalitions must address the specific, concrete, and immediate needs of their at-risk populations.

The evolution of thinking about participation, particularly as it relates to health promotion, has been described by Green (1986) as an older perspective that viewed citizen involvement as "cooperation" with centrally controlled programs. Specifically, health education (paralleling the critique of citizen participation in horizontal coalitions) stressed teaching people to follow instructions and to make use of centrally planned services. Over time, health educators and health promotion initiatives recognized the need for more meaningful participation and control of health care issues. In addition, health care professionals realized that organizations and agencies outside the health field were needed in the promotion of health, particularly organizations addressing quality of life and economic development. Green (1986) also describes the current perspective on participation in health promotion as operating on a principle requiring the involvement of individuals in defining problems, prioritizing needs, controlling solutions, and evaluating progress.

Although many features of this current perspective on health promotion have been addressed previously in this chapter, methods of citizen involvement in evaluating progress may be particularly helpful in the development of Appalachian cancer control coalitions. Participatory research is an approach to evaluation that involves the many members of a coalition in evaluation design and interpretation (Chavis et al. 1983; Ketterer et al. 1980). Within community coalitions, committees provide a helpful structure promoting participatory evaluation. For example, an evaluation committee can operate with representatives from many levels of the coalition (e.g., leadership, organizational members, staff) providing input to the evaluation design to ensure that the evaluation provides useful information to all parties involved. The most important feature of participatory research is that coalition members receive a frequent and steady feedback of information about coalition processes and impacts so that this information can inform coalition decisions (Ketterer et al. 1980). Evaluation findings should be tailored to individual audiences to ensure the usefulness of the information. The use of participatory evaluation in Appalachian cancer control coalitions may assist in the coalition's development and support broad participation.

Challenges to Health Coalitions

Community health promotion and disease prevention coalitions face several challenges. The health care issue is dominated by health professionals; consequently, individuals often have a passive orientation to their own health status. Therefore, involving individuals in preventive health care presents a difficult challenge.

One challenge to community coalitions involved in health promotion is that they must address the needs of the at-risk populations they serve. However, these populations often perceive themselves as having much more immediate needs than cancer prevention and screening. Much knowledge exists on how to prevent and detect cancer early, and community coalition literature can optimize methods of reaching at-risk populations. Nonetheless, the challenge that health promotion coalitions must address is how to involve individuals in cancer control once they have been reached. Perhaps the most effective strategy for involving individuals in health care coalitions is to have coalitions focus on the needs of at-risk populations. This strategy is based on coalitions addressing

the primary needs of at-risk populations—needs other than health issues—and addressing cancer prevention and control activities only secondarily.

As discussed earlier, coalitions focused on health care issues must be aware of the challenges faced by coalitions stressing community participation in health promotion. First, the infrequent use of the health care system makes it difficult to mobilize the community around health. Second, those most often affected by health care issues, such as the elderly and the acutely ill, are those least able to participate in a coalition. Third, the factors in the environment and health care system that contribute to poor health are difficult to perceive, particularly around the issue of health care.

Conclusion

Despite these and other difficulties mentioned, community coalitions organized for health care issues can be successful. The issues discussed in this chapter reflect challenges rather than obstacles to forming and developing community coalitions. By considering these issues throughout the course of coalition development and continually reflecting on the principles articulated, cancer prevention and control coalitions in Appalachia offer a promise of success.

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CHAPTER 8

Action Steps

1. Research additional coalition models and study the ways in which community-based coalitions are formed and structured and how they function.

2. Develop coalitions with members from diverse local community groups. Be sure that coalition members have links to all organizations and groups essential to the successful implementation and conduct of coalition activity.

3. Recognize the different categories of coalition member organizations, especially advocacy-oriented organizations and service-oriented organizations.

4. Be realistic about the time and effort coalition members can devote to coalition efforts.

5. Create linkages of coalition members with hospitals, schools, businesses, social service agencies, and government agencies to better address local adverse environmental and social conditions; design a more comprehensive approach; provide greater access to community residents; and increase community ownership and participation in coalition activities.

6. Keep in mind the context factors of any cancer prevention and control coalition, including increasing utilization of the health care system, enabling elderly and acutely ill persons to access community resources, and identifying the environmental and systemic forces contributing to poor health.

7. When recruiting coalition members, clearly articulate the unique needs your coalition seeks to address, focus on how its goals affect prospective coalition members, and identify the benefits of coalition membership to each particular organization or agency.

8. Recruit coalition members who know the stories and histories of people who live in the community and who have an indepth knowledge of how certain issues affect the residents of the area.

9. Consider the stability and capacity of the organizations that coalition members represent. Be sensitive to resource constraints such as staff, equipment, and budget levels. Be aware that different levels of participation can result from different amounts of resources.

10. Identify coalition leaders who are able to deal effectively with problems such as distribution of power, turf issues, and conflicts of interest or who have unique skills such as the ability to articulate and share the coalition's vision and potential for success.

11. Clearly define the coalition's purpose and member roles to build the trust and cooperation necessary to address issues effectively.

12. Make clear initially and continue to review the four factors of coalition maintenance: domain consensus, ideological consensus, work coordination, and evaluation.

13. Use coalitions to identify the needs of the at-risk populations they serve.

14. Involve the at-risk populations in cancer prevention and control efforts.

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CHAPTER 9

Lessons From Other Coalition-Based Programs of the National Cancer Institute

Judith Swan and Karen Fraim Goss

Introduction

This chapter reviews the coalition experience of the National Cancer Institute (NCI) programs in cancer prevention and control. Its purpose is to highlight recent activities that have used coalitions and point out promising avenues of approach for this type of research application. The experience covers an array of variants that come under the definition of "coalition," from physician networks to industry partnerships to citizen groups. The goals set by these associations have varied as well. Because most of the projects that involve coalitions were ongoing at the time of the chapter's preparation and the results of their efforts largely unpublished, the authors conducted interviews with the NCI staff members who serve as program managers for these projects to gain their views of coalition formation and maintenance. In addition, several draft reports of coalition activities were made available by the project personnel to provide general information on coalitions and community mobilization. Formal evaluations of most of these coalitions have not yet been completed.

In addition to NCI, many other funding sources support coalition-based programs that target cancer. Among the largest of these are the American Cancer Society (ACS) and the Centers for Disease Control and Prevention. As with the NCI programs, most are directed at achieving the *Healthy People 2000* (U.S. Department of Health and Human Services 1991) objectives as described in Chapter 6 of this volume. NCI initiatives are highlighted in this chapter to facilitate the reader's view of the coalitions as a part of the cancer control research paradigm, an orderly process that moves scientific discoveries from the laboratory to clinical trials to community application, as described below.

Later in the chapter, examples are presented of NCI-supported projects that have involved coalitions. Some projects included groups of people who agreed on certain goals and formed coalitions to bring about change; their experiences are relevant to the coalition models. Because these have largely been research efforts and therefore somewhat proprietary in nature, interactions among projects have been limited, except where noted in the discussion that follows. As previously stated, the NCI projects remain substantially unpublished because of their relatively recent inception. This chapter represents a preliminary gathering of evidence to provide an impression of, and some insights into, the use of coalitions to accomplish research goals and apply research results.

Coalition Models at NCI—Rationale

In recent years, coalitions have become integral to many of NCI's efforts in cancer control research. Although the earliest organized cancer control efforts in the United States were

led by the surgeons who confronted cancer daily (Breslow et al. 1977), the recent pressures for greater advancements and their widespread application have come more from public health practitioners, patient advocates, and grassroots organizations. The theory and principles behind the practice of coalition building are described by Speer and Chavis (this volume); in addition, NCI's reasons for including this activity as part of its research agenda can be followed in its interactions with Congress over the years.

Congress emphasized the Institute's cancer control aspects with passage of the National Cancer Act in 1971, which was amended in 1974 to authorize a separate amount of funding for these activities to highlight their significance. Some of the first initiatives developed in the early 1970s were community-based cancer control programs. However, the emphasis for years remained on basic and clinical science as new discoveries were pursued and continuing commitments for ongoing research were met. Over the past decade, NCI has strongly emphasized the development of research application programs, beginning with its tobacco control programs. The impetus came from the recognition that advances in medical technology and public health were too slow in reaching physicians, patients, and the general population, a concern reiterated by Congress in authorizations that have succeeded the National Cancer Act and echoed the 1974 law:

> *The Director of the [National Cancer] Institute shall establish and support demonstration, education, and other programs for the detection, diagnosis, prevention, and treatment of cancer....Programs established and supported under this section shall include...locally initiated educational and demonstration programs (and regional networks of such programs) to transmit research results and to disseminate information respecting...the detection, diagnosis, prevention, and treatment of cancer... (Public Health Service Act, Section 412, 1993, pp. 284-285).*

In the years following the mandate of the National Cancer Act, Dr. Peter Greenwald, director of NCI's Division of Cancer Prevention and Control (DCPC), further developed the concept of cancer control research by describing it in a logical stepwise fashion, based on a scientific framework and methodology. In a landmark paper delineating the process, the authors stated:

> *Until the 1980s, cancer control was not defined in terms of research, but almost exclusively as a "demonstrational" program. This approach implied that effective intervention methodologies existed when in fact they often were not available or were still under development. The flexibility and creative thinking characteristic of the biomedical research process must be preserved, but other considerations associated with research on human interventions—efficacy, costs, safety, and ethical issues—support the need for well-defined process (Greenwald et al. 1987, p. 393).*

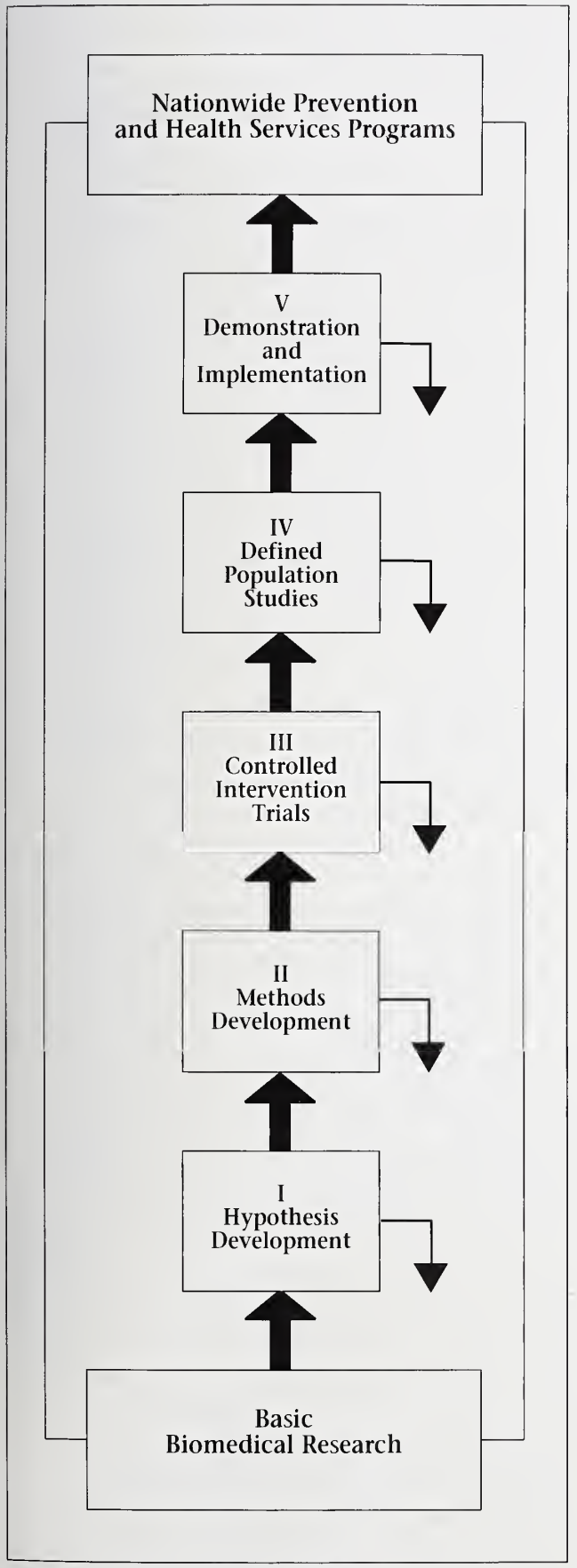
Dr. Greenwald's scientific logic for cancer control research paralleled the continuum of clinical research, emanating from laboratory or epidemiological evidence and proceeding through an orderly sequence of five phases:

- Phase I—hypothesis formation for cancer control strategies beginning with a systematic review of existing data and information;
- Phase II—identification and development of intervention tools and research methods;
- Phase III—controlled efficacy studies in selected groups of individuals;
- Phase IV—studies in defined populations to determine the potential benefits for demonstrations in large populations; and
- Phase V—demonstration and implementation studies. There is a decision point at the end of each phase to determine whether the results indicate proceeding to the next phase. As the process moves ahead, information is fed back to help researchers refine their course according to the effectiveness of the strategies. This approach ensures that only proven strategies will reach the implementation phase and gives priority not only to cancers deemed to be causing the greatest burden but also to interventions that have demonstrated efficacy and are ready for widespread application. These steps in the decision-making process are summarized in Figure 1.

It is apparent from this schema that the coalition fits into the latter phases and can help to bridge the gap from scientific validation to nationwide dissemination of cancer control information and application. In addition, it can provide fertile ground for hypothesis generation in the process of developing more targeted application methodologies. The information presented in this chapter is part of the feedback process described above. Although the experience varies within NCI because of the disparate types of coalitions formed and the various time periods over which they have been active, similar patterns reappear throughout.

The following summary describes the program goals, successes, and pitfalls in the formation and continuing support of coalitions, which may be applicable to the efforts that will be undertaken for the Appalachia Leadership Initiative on Cancer (ALIC). The project descriptions are summarized from the 1992 *Annual Report of the Division of Cancer Prevention and Control* (National Cancer Institute 1992a) or the 1992 *Report of the Special Action Committee* (National Cancer Institute 1992b). They are not intended to be totally inclusive of the work supported by NCI but to be a representative sample of the most visible projects that have utilized the coalition approach to cancer control. This chapter is not intended to present the results of their interventions, which is the prerogative and responsibility of the project investigators.

FIGURE 1. Phases of cancer control research



Source: Adapted from Greenwald et al. 1987.

Examples of Coalition Models at NCI

Control of Tobacco Use— Some of the Oldest NCI Coalitions

Some of NCI's early work involving coalitions arose from its Smoking, Tobacco, and Cancer Program (STCP), whose leaders realized early on that the federal sector alone could not begin to approach the national goal of a smoke-free society by the year 2000 (Greenwald 1990). The NCI coordinator of STCP, the late Joseph W. Cullen, Ph.D., spearheaded the development of an aggressive plan of research involving Phase II and Phase III trials to test various tobacco control methods and strategies in selected populations. As a result of these trials, investigators found that simple steps applied broadly were effective, such as physicians and dentists advising their smoking patients to quit and helping them through local cessation programs. Small interventions for large populations, including the use of media to discourage smoking, proved more useful that the development of new and unusual technologies for bringing about behavior modification (Cullen 1990). Consensus meetings of trial investigators were held to synthesize the essential determinants of successful antismoking interventions. From this synthesis, the logic of the cancer prevention and control phases led to the development of COMMIT, the largest smoking intervention trial in the world.

Commit

The Community Intervention Trial for Smoking Cessation (COMMIT) directly involves some 2 million people—and indirectly millions more. According to the process described above, this is a Phase IV trial with the specified target population of heavy smokers (defined as persons smoking more than 25 cigarettes per day). Its design includes 11 pairs of communities in the United States and Canada matched for size, population characteristics, and location. Implemented in 1988 after 2 years of planning, COMMIT has been

testing the effectiveness of community-based interventions in decreasing smoking and, more specifically, whether the implementation of a defined intervention protocol, delivered through community organizations with limited external resources, would result in a "quit rate" among heavy smokers of at least 10 percentage points greater than in the comparison communities that did not receive intervention. The overall goals of the trial have been to increase the priority of smoking as a public health issue, improve the community's ability to modify smoking behavior, increase the influence of existing policy and economic factors that discourage smoking, and increase the prevalence of social norms and values that support nonsmoking. Results from previous intervention trials provided numerous strategies for the COMMIT protocol, the most promising being offered through physicians and dentists, mass media, worksites, community organizations, and community telephone hotlines. Table 1 lists the areas of emphasis and examples of COMMIT interventions.

To standardize the interventions as much as possible and to achieve meaningful comparison between intervention and comparison communities, COMMIT investigators adopted a protocol of required activities with definite goals and measurable process outcomes. Execution of the protocol required the formation of partnerships with communities and the establishment of a community board and several task forces for each intervention site. Initiation of community action and planning for implementation were the responsibility of the local board, which adapted the protocol's mandated activities to their community. Board members included health care providers, hospital directors, media experts, representatives from voluntary health organizations, and community business leaders. The board provided the interface between the trial investigators and the community and determined which resources were needed to carry out the protocol. Members of the board were chosen by the trial investigator together with a core group of community leaders, based on an extensive pretrial community analysis. This analysis included not only an assessment of smoking patterns and potential intervention channels but also a study of community organizations and leadership, political structure, and cultural climate. To avoid premature mobilization, information was gathered largely from secondary sources (National Cancer Institute 1991). Eventually, the board members added leverage to the protocol through their own promotion of its health goals and recruitment of additional coalition members. As time went on, the investigators were able to make adjustments that improved the adaptation of the protocol to the communities. The 4-year effort eventually involved more than 1,000 physicians, 700 dentists, 1,400 worksites, 1,000 community organizations, 250 media outlets, 400 schools, and 60 cessation service providers. Evaluation is a major component of COMMIT, consuming one-fourth or more of its defined budget.

The fieldwork of this trial was completed in early 1993, to be followed by an intense period of data collection and analysis. Because the results of the protocol are blinded, the final outcomes remain unknown as this monograph goes to press, although several articles on process analysis have been published. Nine of the eleven intervention communities thus far have developed plans to continue their smoking prevention and intervention activities after the funded protocol ends, a testament to the institutionalization efforts of the community coalitions. In addition, numerous materials and resources are becoming available for widespread dissemination, including a how-to guide for working with unions and a handbook on community health promotion. Foremost among its accomplishments is COMMIT's demonstration that "diverse communities can be organized and mobilized around important health issues. It can be further demonstrated that organized and mobi-

TABLE 1

Examples of COMMIT intervention activities

Intervention Task Force	Public Education	Community Activities	Policy/Economic Activities
Health care	Motivate smokers to seek cessation assistance from health care providers.	Promote physician/ dentist/ pharmacist training. Expand cessation programs.	Seminars/ consultation to promote no-smoking policies.
Worksites	Promote worksite smoking behavior changes (presentations, posters, newsletters).	Support worksite cessation programs (self-help manuals, audiovisual materials, incentives).	Develop smoke-free worksite policies.
Organizations	Make presentations at meetings and in organizational media.	Promote community cessation resources, large organization self-help programs.	Promote smoke-free meetings and organize "magnet events."
Cessation resources/services	Supply information on health consequences, quit resources, maintenance, passive smoking.	Supply counseling, self-help materials, referral to cessation programs through telephone hotline.	Refer to community resources to change policies. Information on regional/national smoke-free policies.
Public education (media)	Sponsor "kickoff event" to publicize other activities, media training for local advocates, local amplification of national events.	Supply self-help information, referrals to cessation resources, including hotline.	Publicize policy changes in local institution and raise the passive smoking issue.
Schools	Adapt school curricula, student/parent materials, teacher training.	Promote parental cessation through youth, combined parent-cessation/ adolescent-prevention programs.	Promote smoke-free school policies, sports, other public events.

Source: Adapted from Shopland and Massey 1990, p. 55.

lized coalitions can effectively implement research aimed at reducing tobacco use and cancer" (W. Lynn, personal communication, December 24, 1992).

A summary of the COMMIT community mobilization experience was prepared by several of the investigators and experts on community analysis (Thompson et al. 1993). This report focuses particularly on the achievement of objectives for community partnership and on the generalizable aspects of COMMIT's community mobilization efforts. Across the 11 intervention communities, progress, board composition, and approaches to solutions varied, but several common themes affected them all, as summarized here.

► Because of the demands of the protocol, there was not much time available to the newly formed coalitions for developing the internal cohesion necessary to accomplish the required tasks. Initial challenges under this time pressure included gaining the interest of potential volunteers and conquering volumes of written information.

► It was helpful to include as board members those individuals with experience in civic projects that crossed several areas of special interest and required cooperation among a broad array of organizations. The initial community analysis was crucial to the identification of these individuals. At the same time, the investigators had to remember the nature of volunteer work and that each individual usually had limited time to donate to the project. Therefore, widening the network of volunteers helped to sustain the overall effort.

► The roles and duties of the research institutions versus the community groups needed to be clearly defined. This was important to achieve community ownership of the project and was a negotiated and renegotiated process. Lack of clarity was an ongoing reason for mistrust of investigators. Information on budgetary responsibilities, constraints, and mechanisms had to be available and particularly clear in definition.

► Demographic factors such as community size, location, and diversity made little difference in the degree of mobilization that could be achieved.

► Part of the motivation for board members was the feeling of "uniqueness" of the community and the sense that the local leaders knew more about getting results in that community than the investigators. Allowing for local initiative and creativity was one of the strengths of the COMMIT protocol, which helped to maximize the contributions of local resources. At the same time, another agenda could be developing within the community, and project leaders needed to be sensitive to larger needs for civic action.

► Training for board members was an important asset, even for those with coalition experience. Training in conflict resolution, organization management, media advocacy, and influencing health care providers was provided centrally by NCI or by consultants who acted as facilitators. Centralized training also provided an opportunity to recognize the accomplishments of the board, an important gesture that served to maintain momentum.

Overall, COMMIT met its community mobilization goals in all the intervention sites. Nevertheless, community ownership was slow to evolve, and it was important to recognize and resolve conflict as soon as it arose. Tension and conflict, in fact, were to be expected, and communication was the key to progress. Apparently, the boards were happy to work within constraints as long as they knew exactly what the limitations were, and every site reported positive benefits for the program and the community's involvement (Thompson et al. 1993).

Assist

One place the results of COMMIT will be applied more broadly is the American Stop Smoking Intervention Study for Cancer Prevention (ASSIST), a collaborative effort between the National Cancer Institute and

the American Cancer Society, along with state health departments and other voluntary organizations, to develop comprehensive tobacco control programs (Glynn et al. 1990). Currently awarded as contracts to 17 state health departments, ASSIST is a true Phase V demonstration project, initiated to confirm that the widespread, coordinated application of the best available intervention strategies will significantly accelerate the downward trend in smoking and other tobacco use and result in a substantial reduction in the number of tobacco-related cancers in the United States. ASSIST has two specific objectives to reach by the year 2000 in its intervention communities: to demonstrate and evaluate ways to accelerate the decline in smoking prevalence to less than 15 percent of adults and to reduce the number of new smokers among adolescents by 50 percent. Population groups whose smoking rates remain a problem (such as women, the medically underserved, the less educated, and several ethnic minority populations) will be specially targeted at the intervention sites.

ASSIST is based on community interventions directed by local voluntary coalitions that will plan and implement tobacco control activities. It will not provide direct support for health services but will mobilize communities to reach the target groups, using the health care system, schools, worksites, and other community channels. Specific interventions include training health care providers to deliver cessation counseling, implementing smoke-free policies in schools and worksites, and enhancing media coverage of tobacco use issues. NCI estimates that ASSIST will reach 18 million smokers and that, through its influence, more than 4.5 million adults will quit smoking and 2 million adolescents will be prevented from becoming addicted. Overall, it is expected that 1.2 million premature deaths will be averted, including 422,000 deaths from lung cancer. The 17 state health departments selected for funding are in a 24-month planning period at the time of monograph preparation. The 5-year intervention phase began in 1993 and will continue through 1998. Contracts were awarded to public health departments in Colorado, Indiana, Maine, Massachusetts, Michigan, Minnesota, Missouri, New Jersey, New Mexico, New York, North Carolina, Rhode Island, South Carolina, Virginia, Washington, West Virginia, and Wisconsin. NCI's Cancer Information Service, among others, has been working on the development of educational materials for ASSIST. A legislative policy component in the program, when coupled with the public programs developed by the coalitions, could produce significant progress in improving the nation's health. The state health departments are working with ACS to maximize the potential for the coalitions to continue their activities after federal support has ended. Evaluation of ASSIST will come from activity profiles, qualitative reports, site visits, case studies, and meetings at the coalition level.

When the steering committee of ASSIST first met, many program participants saw themselves more as traditional health care providers with responsibility to individual patients than as public health practitioners prepared to target a broader population (R. Marshall, personal communication, December 18, 1992). As their ASSIST-related activities intensified, they began to reach out to non-medical sectors such as businesses, the media, and minority organizations in an effort to engender an understanding of the program's importance among these potential ASSIST partners. In communities where coalition formation was stimulated by NCI, the question of training in public health practice arose among the steering committee members. It eventually became clear that, although it was important to provide training for some participants, it may be difficult—and, in fact, unnecessary—to furnish training for every coalition member. In addition, the need for a planning phase was unclear to many individuals, as

some coalition representatives were eager to initiate interventions immediately in their respective communities. However, they soon began to recognize that data collection—a part of the planning phase conducted by the coalitions through interviews within the communities—was becoming a form of intervention in itself by providing the opportunity to enlarge the network of community contacts. In fact, the purpose of the coalitions was not to replace the existing local resources but to increase their potential for use in the service of ASSIST's goals, and this became more feasible in the eyes of the leadership as the planning phase proceeded. For example, one unexpected reaction of this phase emerged from American Heart Association and American Lung Association representatives who were already working with the state health departments and who felt overlooked because their expertise was not being utilized.

Research Networks in Special Populations

NCI has been forming coalitions of a different kind through a system of networks stimulated by the demand for culturally sensitive researchers to address the unique cancer prevention and control needs of minority and underserved populations. Instrumental in identifying shortages of African Americans, Hispanics, Native Americans, and Native Hawaiians in health care professions, the members of the networks generally are university-associated medical professionals who are in position to attract minority university students and local minority physicians to the arena of cancer prevention and control research. Unfunded except through professional services contracts and conference grants, the networks examine barriers to the use of cancer control strategies and state-of-the-art treatment in their communities. The network members recognize the importance of filling the gaps in research and application of research results to their respective populations. For the network participants, special emphasis is placed on developing skills in preparing research plans and grant applications.

National Cancer Control Research Network for Black Populations

The first network established was the National Cancer Control Research Network for Black Populations, which has been successful in stimulating the alumni of the major African-American medical institutions and historically Black colleges and universities, as well as other health professionals throughout the country working in African-American communities, to participate in clinical protocols and to design and implement cancer control measures. This network also provides a computer-assisted mechanism for identifying and involving other nonminority institutions in research efforts that augment the activities of the network.

National Hispanic Cancer Control Research Network

Following the precedent of the African-American network, the National Hispanic Cancer Control Research Network (NHCCRN) was formed to increase the number of Hispanic investigators involved in cancer prevention and control studies. There is strong incentive for this effort because the early intervention and data collection efforts have been unable to recruit, retain, and adequately survey Hispanic populations. The network's long-term goal is to improve this situation, and it will tap the resources of its membership, which has broad representation among Cubans, Puerto Ricans, and Mexican Americans, to help address the great diversity that exists among these groups (E. Ruiz, personal communication, December 18, 1992).

The progress achieved thus far by NHCCRN can be seen in the success of its 1991 North American Conference on Cancer in Hispanics and the grant-writing workshop held during

the conference to assist Hispanic researchers in applying for grants. As a result of the workshop, several researchers were successful in their submissions of grant applications for NCI's new National Hispanic Leadership Initiative on Cancer. Based on this experience, the network is publishing a guide for the preparation of grant applications as well as a compilation of existing demographic and research data relating to Hispanic populations as resource documents for planning future cancer intervention projects.

Network for Cancer Control Research Among American Indians and Native Populations

The Network for Cancer Control Research Among American Indian and Alaska Native Populations comprises participants from reservations, tribal associations, urban organizations, and the Indian Health Service. These individuals are service providers, academicians, clinic directors, researchers, and organization leaders, and more than half are Native Americans. In 1992, the network submitted a strategic plan for cancer control to the NCI director, addressing data collection, education, and research activities as well as training for researchers and health care providers.

Native Hawaiian Cancer Control Research Network

The Native Hawaiian Cancer Control Research Network conducted its first formal working group meeting in 1991. This network is focusing on the unique cancer needs of the Native Hawaiian population and will encompass a variety of collaborative efforts with *Papa Ola Lokahi* (Native Hawaiian Board of Health established by the Native Hawaiian Health Care Act of 1988), Office of Hawaiian Affairs, Cancer Center of Hawaii, Native Hawaiian health organizations, traditional healers, scientific and lay community leaders, and civic leaders. The overall mission of this collaboration network is to improve the cancer outlook for Native Hawaiians and their *o'hana* (family) and communities through the involvement of Native Hawaiian leadership in research and education programs that are research networks, the building of coalitions is seen as a vital factor in addressing the cancer problems of this diverse population.

The networks offer minority professionals an opportunity to pool resources and ideas and begin to address the cancer control research needs of their respective population. It is often difficult to overcome the barriers that exist. Many of the established pathways for achieving cancer control goals may prevent the populations they target from contributing to the solutions for the problems in their communities. A lack of understanding of the competitive grant process, for example, can discourage individuals from applying for grants. As described above, the NHCCRN grant-writing workshop represents an example of the important changes that the networks hope to make in the scientific community. By offering a type of mentoring for new researchers, the networks continue to have a positive influence on the future of minority investigators. It is a process that will shift slowly as more individuals are identified and encouraged to pursue research. In addition, the networks are attempting to eliminate conflict between scientific method and cultural beliefs, bridging the knowledge gap for both sides.

Initiatives in Public Health Education

Just under way is an NCI program testing public health approaches to increase breast and cervical screening of older, low-income, poorly educated, and minority women. The Minnesota, Rhode Island, and Texas departments of health are forming community consortia that will work to characterize the utilization of local cancer screening services, assess the barriers to their use, and test interventions. This grant program was reissued in 1992, and three new awards went to the

Wisconsin Division of Health, West Virginia University, and Reynolds Health Center of North Carolina. The results of the activities of several of these consortia could provide significant insights to future participants of ALIC.

To promote similar efforts on a larger scale, Louis B. Sullivan, then assistant secretary for health and human services, requested in 1990 that the Public Health Service develop a national early detection plan based on its *Healthy People 2000: National Health Promotion and Disease Prevention Objectives* (U.S. Department of Health and Human Services 1991). Over several months, the National Strategic Plan for the Early Detection and Control of Breast and Cervical Cancer was formulated by a broad spectrum of public, private, and voluntary organizations. At a time of growing public interest in controlling breast and cervical cancers, the plan was designed to provide added impetus to current activities in the field and to define the necessary elements for ensuring regular screening for breast and cervical cancers as well as prompt followup for every woman as recommended under the current guidelines. The targeted population includes not only older, poorer, less educated, and minority women but also the health care community, especially those enlisted to perform the screening services. The plan represents a national framework, based on the *Healthy People 2000* (U.S. Department of Health and Human services 1991) goals, in which there are major roles for federal, state, and local governments; national organizations; the private sector; and the general public. All these groups, including professional medical societies, cancer centers, state health officials, private funding organizations, and coalitions of cancer patients, had input in the development of the plan. The Public Health Service agencies had the responsibility for assembling the plan, but implementation will include the formation of coalitions at state and local levels. The talents and resources of the people living within the various regions of the country will be called on in the process. The expertise of NCI's Cancer Information Service, through its regional offices and its computer information system (Physician Data Query), will assist in the plan's execution. In addition, passage of the Breast and Cervical Cancer Mortality Prevention Act of 1990 has provided funding through the Centers for Disease Control and Prevention to support state health agencies in developing effective systems for improving the early detection process for underserved women.

From the plan's inception, the steering committee felt that the key to coalition success would be strong leadership and support from the highest levels of the sponsoring agencies. Eventually, the testimony of 150 individuals was streamlined into a rational plan addressing data collection, education and information dissemination, quality assurance, and access to followup services. A detailed plan for implementation is now under development. The effectiveness of the coalitions will be evaluated by monitoring the number of cancer screenings that take place in targeted communities. The steering committee members foresee that the plan will contribute to the type of community awareness and education that can lead to an active approach to health care among individuals. According to the committee chair, "As far as I am concerned, there is no other way" (E. Sondik, personal communication, December 18, 1992).

Recognizing the central role of public health agencies in translating cancer prevention and control science into practice, NCI has supported 22 grants and cooperative agreements to state health departments under the Data-Based Intervention Research (DBIR) Program. This program has required that each grantee identify and analyze relevant data and, using these data, develop a state cancer control plan. The priorities set forth in this plan then served as the basis for implementing and evaluating

cancer control interventions. The use of consortia and coalitions in the planning process was emphasized. In some cases, these coalitions were already operating under state mandate; in others, the DBIR project provided the impetus for their establishment.

These state-level coalitions continue to focus on data-based planning for cancer control interventions and, in this context, provide important information about the coalition process. Beyond reporting on the types of data and the ways in which data were used by these coalitions, the DBIR projects have begun reporting their evaluations of the use of coalitions and smaller working groups in the planning process. Although many of the larger studies of this process are not yet complete, several observations have become clear across DBIR projects. For the majority, coalition-based planning followed several basic steps, which included establishing the coalition and working groups, identifying available data, defining data characteristics and assessing data quality, and analyzing the data. This procedure provided the ability to define the cancer problem or identify further data needs and to establish cancer control priorities. (Lillquist et al., in press). The role of health department staff, working groups, and the full coalitions shifted as planning proceeded, with health department staff providing the lead role early in the process, when coalition membership was being defined and available data identified, and the full coalition assuming the lead role at the point of establishing priorities for cancer control. The composition of these planning-based coalitions and working groups included many technical experts in cancer control, and these experts served a critical role in ensuring the credibility of the final plans. In the end, the use of a coalition structure for cancer control planning was very labor-intensive but contributed considerably to the state-wide acceptance of the final plans (Haenlein 1992).

The Leadership Initiatives

Among NCI's projects aimed at specifically stimulating coalition activity through community leaders, the National Black Leadership Initiative on Cancer (NBLIC) was the first established. In 1987, the National Cancer Advisory Board, led by member Dr. Louis Sullivan, championed the concept as a health education initiative aimed at mobilizing African-American leaders in an effort to promote NCI's cancer prevention and control goals and encourage the involvement of all African Americans through community outreach programs. The program was conceived as part of an effort to respond to the high cancer incidence rates and accompanying low survival rates among African Americans—rates that, for the past 30 years, have been at considerable disparity with those among white Americans. After a series of regional meetings, the first program was funded from 1989 to 1992.

NBLIC's highest priorities have been the promotion of smoking cessation, diet modification, early detection, and state-of-the-art treatment. Operating through one grantee as national coordinator, the NBLIC structure divided the United States into six regions, each with a director to facilitate and assist in the formation of community coalitions. Approximately 50 cancer prevention and control coalitions have been established thus far throughout the nation. Their activities have linked communities with national health promotion campaigns such as National Minority Cancer Awareness Week, National Prostate Cancer Week, and National Breast Cancer Awareness Month. The regional directors have recruited volunteers, assessed local resources, and served as liaisons between the coalitions and various health organizations. They have played an important role in enhancing communication and cooperation among local health programs, community resource managers, and area cancer survivors.

The accomplishments of NBLIC include the recruitment of well-known African-American leaders as volunteers to promote prevention and control activities in their communities (National Outreach Initiatives Branch 1991). As a result, religious and medical leaders in the Philadelphia area banded together with the media to successfully deter the Uptown cigarette marketing campaign of R.J. Reynolds Tobacco Company, which was aimed primarily at the African-American community. In Harlem, largely because of the efforts of regional chair Dr. Harold Freeman, hundreds of women received free mammography screening. In Atlanta, NBLIC joined forces with another local group to develop a mammography education effort. The Denver coalition offered free and low-cost mammograms to the public. The Milwaukee Mobile Mammography Program provided hundreds of mammograms and taught women how to perform breast self-examination. In the West, the Los Angeles coalition joined with ACS to sponsor Black Cancer Awareness Sunday in several hundred churches that provided educational materials and messages on cancer prevention and control to their congregations. More recent coalition activity in Los Angeles has included the provision of screening services to the local population. Most NBLIC coalition activities have involved the issues of access to cancer prevention and control services and health care facilities (including transportation) rather than data collection and analysis.

Over time, NBLIC has become a well-recognized entity within African-American communities, and it has carried one of the strongest rallying messages for some communities in several decades (V. Cholletté, personal communication, December 21, 1992). The activities of NBLIC have been extended through a new grant program funded in 1992, this time with three principal investigators. One investigator will facilitate outreach activities through minority health professionals and medical schools and will continue to manage the existing regional organizations. The second will address cancer outreach in rural communities. The third will study behavior modification strategies targeted to African Americans. There has been no formal detailed evaluation of the NBLIC program thus far.

The National Hispanic Leadership Initiative on Cancer (NHLIC) is in the planning and development stages, having awarded two cooperative agreements to the University of Texas Health Sciences Center and the National Coalition of Hispanic Health and Human Services Organizations (COSSMHO). Nine local project sites have been established across the continental United States and in Puerto Rico by the University of Texas to address research questions and data collection relating to risk factors, epidemiology, and community-based cancer prevention and control activity. COSSMHO will focus on information dissemination and development of materials. Each grantee has a network of coinvestigators who will reach the 22.3 million U.S. Hispanics and design activities specifically suited to the many groups within this diverse population (E. Ruiz, personal communication, April 12, 1993).

Awards for the Appalachian Leadership Initiative on Cancer, modeled after NBLIC, were made in September 1992. As described in Section III of this monograph, this program targets the Appalachian region.

Another NCI-sponsored research project has explored the use of community leadership for community cancer education programs. Among the projects funded between 1986 and 1992 for the Avoidable Mortality in Black Populations Program, Michielutte and his colleagues at the Bowman Gray School of Medicine applied a systematic method of identifying community leaders in Forsyth County, North Carolina, to assist in increasing the rate of cervical Pap smear screening among African-American women (Michielutte and Beal 1990). They used a "modified snow-

ball" technique through which 10 recognized leaders in the community were initially contacted; in the course of discussing the project, each was asked for the names of other possible contacts in five categories, including social/civic, political, religious, business, and "less visible" leaders. This process was repeated until new names were no longer being generated. It provided the investigators with a large pool of leaders to call on for the development and implementation of the program and helped them to give the community a sense of ownership of the project, which was necessary to achieve continuity of the program at the end of the initial funding period.

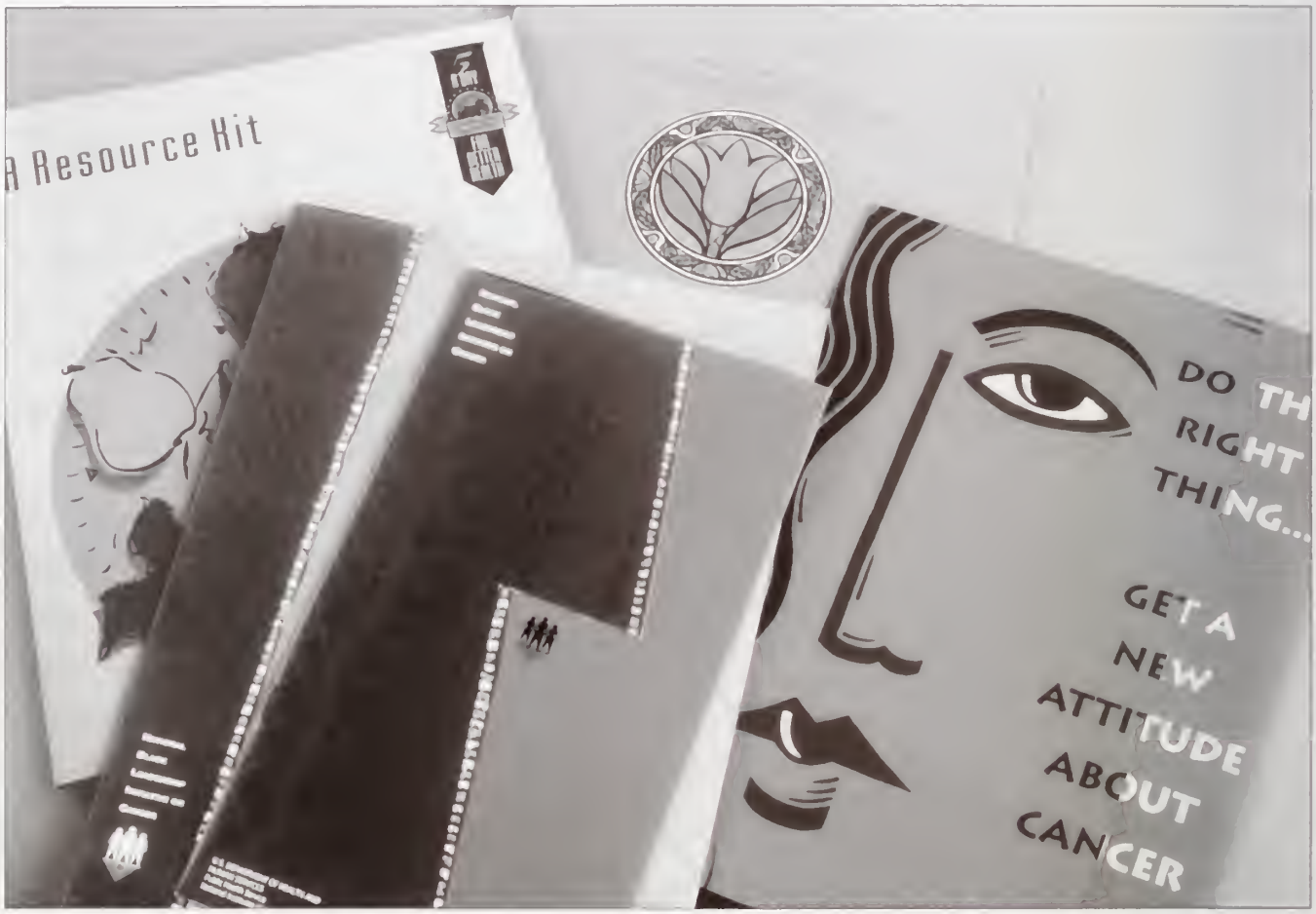
Related NCI Resources

Several of the coalition-based activities described above have used the Cancer Information Service (CIS), in NCI's Office of Cancer Communications, which can provide a unique resource for local outreach activities. Its services include not only a toll-free telephone line for the latest cancer diagnosis and treatment information for both lay and professional inquiries but also local resource directories and educational materials. Specific informational materials are available for several underserved audiences, including African Americans, Hispanic Americans, older Americans, Native Hawaiians, and low-literacy audiences. Examples of these materials, produced for NBLIC and other initiatives, are shown in Figure 2. CIS was used as a referral service for COMMIT, through the toll-free number, 1-800-4-CANCER. In 1993, the program is being restructured to provide coverage for the entire nation from 19 regional offices. In addition to increasing the number of toll-free lines and staff, CIS will expand its outreach capabilities to serve as field offices for NCI's community programs in screening, treatment, patient education, and cancer prevention. NCI plans for CIS to play an increasing role in linking the National Cancer Program (see Chapter 6, this volume) to communities through cancer centers, community hospitals, state health departments, and cooperative groups of researchers.

One of NCI's most promising projects within the Office of Cancer Communications is based on the fact that many Americans cannot read and therefore lack the literacy skills to understand public information campaigns, which are usually aimed at audiences with at least a ninth-grade reading level. This fact has led NCI to prepare guidelines for developing materials for low-literacy readers, based on literacy and communications research and the educational experiences of literacy and health professionals. This guide, which will soon be published, will feature principles that have been proven through experience and practical guidelines for addressing the everyday issues facing authors of low-literacy materials, such as time constraints, organizational pressures, cost, and the publication process. To be titled *Clear and Simple: Developing Print Materials for Low-Literacy Readers*, the guide approaches the development process in a step-by-step fashion. Among its contents are topics related to determining the reading level, pretesting materials with the intended audience, and learning about the audience by using alternatives to formal research.

In the area of dietary health promotion, NCI has recently undertaken its largest partnership ever with private industry in another Phase V effort, the national 5-A-Day for Better Health program, designed to encourage Americans to eat more servings of fruits and vegetables every day. Initiated in 1992, this is a joint project with the Produce for Better Health Foundation, which represents more than 200 food retailer organizations and 30,000 supermarkets. Over the next 5 years, the 5-A-Day for Better Health program will use the marketplace to persuade Americans to eat a low-fat, high-fiber diet as part of a healthy lifestyle. Four-year research grants will evaluate the effect of 5-A-Day activities in schools, workplaces, and other community settings.

Figure 1. Information and educational materials prepared by NCI's Office of Cancer Communications and distributed by the Cancer Information Service



Although local participation may vary, the 5-A-Day program can provide a national resource that could be linked to future coalition activities.

NCI's most important system of data collection is the Surveillance, Epidemiology, and End Results Program (SEER), consisting of 11 population-based cancer registries covering 14 percent of the nation's population. It is the major U.S. system for tracking cancer incidence, patient survival, and mortality. The data are coupled with information on cancer risk factors, prevention practices, and patterns of cancer care. Linkage of SEER's tumor registry data with medicare files has produced several reports on cancer costs by cancer site and stage as well as by treatment phase. These data have been used to assess changes in medical practice that influence observed cancer rates, such as the use of prostatic- specific antigen in detection of cancer of the prostate. Geographic and demographic differences in incidence, survival, and mortality are being studied to reveal factors associated with decreases in cancer risk, including the availability of cancer prevention and control programs. The results of SEER research are available to the entire cancer research community and are published on a periodic basis.

One of NCI's highest priorities is to improve the nation's capability for measuring cancer rates and risks for population segments such as minorities, the elderly, and rural residents. SEER expanded in 1992 to include the 9 million residents of the Los Angeles area, thereby increasing national coverage to 25 percent of the U.S. Hispanic population, 41 percent of Asian/Pacific Islanders, 17 percent of the American Indian population (primarily in the Southwest), and 12 percent of the African-

American population (National Cancer Institute 1993). Collaboration with the Bureau of the Census is improving availability of regional population data to calculate cancer rates for minorities residing in SEER areas. Although SEER currently does not cover Appalachia, NCI plans to continue expansion of the program in 1995 if requested funds are provided. Increased coverage of rural populations is proposed as well as enhancements of quality assurance aspects related to cancer reporting on minority and other special population segments. Technical assistance will be increased to SEER registries and other cancer registries for data-related training and quality control programs. Quality control audits will be provided to non-SEER registries to ascertain whether these registries provide data comparable in completeness and accuracy with SEER's reporting standards. Certification as a SEER affiliate registry not only would provide transfer of technical expertise to these registries but also would enhance state support and augment the availability of national population-based registry data systems for targeting cancer prevention and control activities. The improvements under consideration will enlarge the coverage of special populations and enable the program to conduct a series of detailed population studies on patterns of early detection, access to prevention and control services, and cancer care. The projects and programs described above, although not community-based coalition efforts, provide materials and information across the country. It is important for program directors and coalition leaders to be aware of these resources and their potential applicability to coalition planning and activities.

Lessons Learned

As stated earlier, much information on NCI's coalition experience was gathered through personal interviews with NCI-level program directors and staff. The following is a synthesis of their remarks reviewing their experiences in managing the projects described in the previous sections.

Those interviewed were almost unanimous in their recommendation that the sponsoring agency provide strong leadership, unflagging support, and open lines of communication. Several mentioned that technical assistance and training for coalition leaders in preparation for outreach activities have been important factors in coalition success. At the same time, power must be balanced between the coalitions and the funded investigators. If the activities of the coalition are to be successful, the coalition must be given the prerogative to initiate activities and be allowed to settle its own intracoalition conflicts. The ability to relinquish power as needed to the coalition can evolve over the life of the funded project. The NCI-level leadership must work to balance the control of the project between the investigators and the community coalition leaders. According to several NCI-level program directors, it is important to understand that NCI and its funded investigators are not providing the coalition's power but are sparking the coalition to empower itself so it can function successfully as a group effort. Several program directors noted that it is easy to underestimate the capability of a coalition, the astuteness of its members, and their influence within the community. Each member can become a resource for the entire group. Because of time limitations for funded projects, it was important to establish an agenda for activities as soon as possible after formation of the coalition and to set specific goals. One NCI staff member cautioned that care must be taken when providing additional money to an established coalition because it could lead to the coalition's demise—by altering its focus—even if the coalition is functioning well.

The COMMIT experience demonstrated that it is important to bring local people together to *uncover* existing resources rather than to *replace* them. Once the coalition is operational and accepted in the community, it can begin

to address any necessary additions or changes. Within the coalition, challenges included matching talents, sharing resources equitably, and motivating members to participate beyond the planning phase and into the implementation phase. The more active members had an interest in the outcome of the projects in which they were involved. In this sense, it was important to begin coalition formation with an extensive analysis of possible stakeholders in the community. Defining specific and suitable roles for the participants played an important part in the success of the activities.

COMMIT illustrated that the activities of the coalition can grow over time. For example, the use of media can play a much more important role after the first years of organization. Anticipation of this evolving process can help minimize wasted effort and maximize the use of resources. At the same time, the coalition may be more active and powerful in its early stages because of the initial enthusiasm of the participants, making this a good time to line up future resources.

The Avoidable Mortality in Black Populations Program in Forsyth County showed that identifying as many community leaders as possible and asking for their support by telephone interview served as part of the educational process, through a word-of-mouth mechanism. This process helped lay the groundwork by sharing ideas and building consensus at the outset of the program. The contributions of these leaders varied and included activities such as developing and disseminating print materials and promoting educational programs. A quarterly newsletter helped maintain enthusiasm for the project. Perhaps most important, contacting community leaders prior to the development of the intervention demonstrated that community input was an important part of the program.

For all projects, the importance of communicating clearly with coalition members was emphasized repeatedly, particularly about what is expected of them. In addition, communication between regional coalitions can help the individuals to recognize opportunities and potential problem areas and not repeat the unsuccessful efforts of other groups. This communication is particularly important when planning a special event. Sharing resources through joint activities provides the opportunity for the coalitions to function with a broader base, allowing for an immense flow of information. If the coalitions share ideas during the planning stages, they are more likely to feel a stronger commitment to collective success, rather than remaining focused on individual projects that may or may not lead to desired outcomes. Finally, recognition of success at federal and state levels can provide an incentive for continuing action at the local and regional levels. This effort can take the form of certificates of appreciation, special reports in project newsletters, or formal recognition by Institute leaders. According to several NCI program directors, this approach promotes goodwill and strengthens local support for the coalitions.

Fostering a balance between community ownership and NCI direction can, at times, be a challenge. Within NHCCRN, achievements resulted from the network's formation as a common vision among the Hispanic populations who participated and its implementation as a democratic process where all shared equally in developing the agenda. In a practical sense, coalition members found they were able to set timetables for objectives by scheduling meetings with specific goals (they currently meet two times per year). A strong steering committee and, in particular, an ardent chairperson were able to direct the network activities, deal with bureaucratic issues, bring ideas generated in the committee to productive closure, and interpret the program goals for individuals and groups outside the

network. The leadership provided by the steering committee chair and the NCI staff allowed other members to embrace the plan and tackle projects without loss of momentum. It was important for them to emphasize the support NCI was giving to NHCCRN and its goals because some members of the public and potential coalition members view government institutions as large bureaucratic obstacles to progress rather than as motivators for positive change. Because of the efforts of NCI staff members, network participants felt they had a partner at NCI. At the same time, this rapport between the NCI staff and the network members was consequential in maintaining the network's focus on its main objectives because it allowed for persuasive reemphasis of project goals.

Within NBLIC, the expertise and leadership of the regional directors were instrumental in the achievements of the coalitions. For example, cooperation with the media has been a key factor in the success of many coalition activities, and several of the regional directors had a great deal of experience and knowledge in media relations. In Georgia, several coalition members were state legislators and thus were able to help bring about the passage of a bill requiring insurance companies to cover the cost of screening mammography and Pap tests. The NBLIC coalitions were groups of volunteers, and, therefore, any change in leadership at the regional or coalition level brought an adjustment period, which meant that the objectives for that area might not be met within the timetable. The most surprising aspect of the overall project was the original community reaction. For a population already facing many issues in need of attention, cancer was seen as an additional burden unfairly apportioned to them, a problem for which there remained few resources and little motivation to confront after decades of dealing with other serious issues within their communities. This reaction was difficult to overcome. NBLIC was asking the communities to take action without providing the financial resources for the coalitions' needs. The communities often felt as though they were being given a directive without the necessary guidance and support. In spite of this, the African-American community began to reunite through the activities of NBLIC, largely because many coalitions had strong local leadership. From the early stages, these leaders linked coalition activities to existing local institutions to provide community awareness and support to NBLIC. This link gave community members cause to consolidate by evoking a shared vision of increased awareness about cancer. The process began to override the initial negative reactions because it had become important to address the special health issues of African Americans. The coalitions had developed the ability to answer community concerns more fully and to bring about change. NBLIC is now recognized and respected by African-American communities and leaders across the nation.

Conclusion

NCI's experience in supporting coalitions for cancer prevention and control efforts is not unusual. The uniqueness of NCI's practice lies in its use of the coalition as part of the investigational program in the final phases of a defined approach to cancer prevention and control research. Because it translates research results to actual use, the coalition is becoming increasingly important to the widespread application of scientific advancements. This growing emphasis on applications research has required, in turn, greater leadership skills among coalition participants, along with an ability to adjust to changing needs and resources. The fact that coalitions must blend the special interests of its members to target common goals has demanded an acceptance of diversity and appreciation for differences among involved individuals and groups.

In addition, the delivery of cancer services to rural populations can face tremendous obstacles because of a scarcity of resources and lack of cancer specialists. Although the national network of NCI's cancer centers and Community Clinical Oncology Programs (CCOPS) represent an extraordinary potential resource for underserved communities across the United States, these institutions are often not located within reasonable commuting distance of all rural areas. Beyond ALIC, therefore, NCI is working to remedy some aspects of rural cancer care through improvements in local infrastructure by launching a 5-year research program to test approaches for linking rural providers and regional oncologists and evaluate outcomes indicative of changes in cancer diagnosis and management. Six projects were funded in 1992 with interventions that will include training of rural physicians, nurses, and pharmacists; establishment of rural cancer clinics and consultation services; implementation of specialized communications systems; and use of community facilitators and cancer control advocates.

For NCI, the support of coalitions has meant providing the long-term commitment on which coalition members can rely. At the same time, community coalition formation offers a less expensive alternative to other types of cancer prevention and control research initiatives. The evaluation of on going projects such as COMMIT and ASSIST will provide valuable information on the uses of coalitions and prompt other questions for examination in future projects. For example, cost control has been addressed only indirectly in most cases, as in the "cost" of morbidity and mortality caused by cancer or as in the provision of free or low-cost services on a short-term basis. To be effective, medical advances must be affordable, and this type of information could be accumulated by community groups.

CHAPTER 9

Action Steps

1. Use the ALIC network of community-based coalitions to generate, test, and implement additional targeted interventions of cancer prevention and control.

2. Organize and mobilize diverse local resources around cancer-related issues, and call on them to implement and evaluate interventions aimed at reducing incidences of cancer.

3. Clearly define roles and responsibilities of coalition members, foster open communication, and promote community ownership of the project.

4. Train coalition members in skills such as conflict resolution, organization management, media advocacy, and outreach.

5. Mobilize local resources to reach target groups in multiple settings such as schools, worksites, churches, the health care system, local shopping centers, and other community settings.

6. Pool resources and ideas from the network of local organizations to address the cancer prevention and control needs of various groups.

7. Evaluate the utilization of local cancer screening services, assess barriers to their use, and test new outreach efforts.

8. Address research questions and data collection methods to assess risk factors, cancer occurrence, and prevention and control interventions.

9. Develop materials suitable for low-literacy readers and implement programs that take into account their special needs and circumstances.

10. Use materials, information, and other national resources such as the National Cancer Institute's Cancer Information Services (CIS) and SEER programs in coalition planning and activities.

11. Emphasize the capability of a coalition, the astuteness of its members, and their influence in the community.

12. Work to balance the roles of project staff and community coalition members.

13. Establish an agenda for activities and set specific goals of the coalition.

The cancer, nutrition, and tobacco use objectives of *Healthy People 2000* (U.S. Department of Health and Human Services 1991) provided added impetus for several of NCI's coalition projects. The application of these objectives to rural areas is presented in Speer and Claus (Chapter 6, this volume). In addition, Congress has expressed concern over rural health and has strongly supported NCI's actions in extending SEER coverage to Appalachia (U.S. Senate, Committee on Appropriations 1991) and in establishing the Appalachia Leadership Initiative on Cancer. However, long before these events, NCI scientific leaders envisioned the use of coalitions for reaching poor and underserved populations. It was the need for application of the latest research advances for the largest benefit that mandated the development of the cancer prevention and control research phases in which coalitions would play a vital role.

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CHAPTER 10

Activists and Advocates as Actors in Health Care

Mary K. Anglin

Introduction

Recent years have witnessed the development of a patient activist health care movement that includes grassroots organizations established by and for cancer survivors. Such groups offer patient advocacy, serve as clearinghouses for information on treatment options, and work to change priorities in biomedical research and to develop new health care services and new approaches in existing services. This chapter presents material on cancer advocacy groups, primarily organized around breast cancer, to describe the ways in which women operate as consumers of health care and informed contributors to health care policy. Health care activists, such as those described in this chapter, represent an important dimension of the kinds of community-based cancer coalitions envisioned by the Appalachia Leadership Initiative on Cancer (ALIC).[1]

Activists and Advocates

The breast cancer movement is an instructive example of recent health care activism for many reasons, not the least of which is the dramatic rise in the incidence of breast cancer in recent years (Kelsey and Gammon 1991; American Cancer Society 1991a). According to figures provided through the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI), age-adjusted incidence rates for breast cancer increased by 27.5 percent between 1980 and 1987 to an incidence rate of 112.4 cases of breast cancer per 100,000 (Miller et al. 1992). An estimated 12 percent of all women in the United States will be diagnosed with breast cancer and 3.5 percent will die from the disease (Harris et al. 1992; National Center for Health Statistics 1990; Blot et al. 1987). In 1992, for example, an estimated 181,000 women received new diagnoses of breast cancer and 46,300 women died from the disease (Miller et al. 1992).

Breast cancer is currently the leading cause of death for American women age 40 to 55 (Harris et al. 1992; National Center for Health Statistics 1990). Overall mortality rates for breast cancer have remained stable since the 1950s. However, for women under age 45 at diagnosis, mortality rates have declined since 1950 by approximately 15 percent; for women over age 55, they have risen by that same percentage (Harris et al. 1992; Long 1993). In addition, it is argued that African-American women and economically disadvantaged women, in particular, experience disproportionately high rates of mortality from breast cancer because of late-stage diagnoses and inadequate access to health care (Baquet and Ringer 1986; American Cancer Society 1986, 1991b; Farley and Flannery 1989; Richardson et al. 1992).

Efforts to prevent breast cancer have proven largely unsuccessful so far. Research has been conducted to identify risk factors for breast

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cancer, including age, family history of breast cancer, prior breast cancer, benign breast disease, age at menarche, nulliparity, age at birth of first child, age at menopause, obesity, height, diet, alcohol use, use of oral contraceptives, and postmenopausal estrogen-replacement therapy (Harris et al. 1992; Henderson 1990, 1993; Giovannucci et al. 1993; Friedenrich et al. 1993; Romieu et al. 1989). However, even when these factors occur in combination, they account for only 25 to 30 percent of breast cancer diagnoses (Henderson 1993).

The search continues for risk factors that might better explain the rising numbers of breast cancer cases and that might be modified by intervention strategies. One possibility currently under consideration is exposure to environmental contaminants, such as pesticides, that might have carcinogenic properties (Krieger 1989; Westin and Richter 1990; Falck et al. 1992; Wolff et al. 1993).

At the same time, researchers are exploring the possibility of "chemoprevention" of breast cancer through the use of tamoxifen, a hormonal agent known for its "antiestrogenic" properties and frequently employed in adjuvant, or secondary, treatment for breast cancer (Henderson et al. 1993; Jones and Powles 1991; Jordan 1990). The tamoxifen trial, currently sponsored by NCI, seeks to enroll 16,000 "high-risk" women, who will be randomly assigned to receive either tamoxifen or a placebo. Trial participants will take the agent assigned them—without knowing its identity—for the next 5 years, while researchers study the effects of tamoxifen use on the incidence of invasive breast cancer and breast cancer mortality rates (Henderson 1993).

The tamoxifen trial is not without controversy because of side effects reportedly found in laboratory animals and in humans receiving the drug (Rutqvist 1993; Han and Liehr 1992). Furthermore, a congressional hearing

held in October 1992 found that scientists "failed to meet the minimum requirements" in warning trial participants about potential side effects of taking tamoxifen (Burd 1992). Nonetheless, the tamoxifen trial remains the primary research effort aimed at the prevention of breast cancer.

In the absence of any proven methods for breast cancer prevention, the dominant strategy continues to be reliance on screening programs, principally through the use of mammography, to detect breast cancers in the population at large (Miller 1991). The argument that informs this strategy is that if breast cancers can be detected at an earlier stage of development, they might be more amenable to treatment (Rutqvist et al. 1990). There are problems with this approach because mammography is expensive and has limited diagnostic value for women under the age of 50 (Shapiro 1989; *Lancet* 1991; Eddy 1989). In addition, the capacity to detect breast cancers when they are relatively small (less than 2 centimeters) does not always mean a reduction in mortality because some forms of breast cancer metastasize early in the evolution of the disease (Harris et al. 1992).

Given rising incidence rates and current limitations in methods of detection and prevention of breast cancer, it is not surprising that women have declared breast cancer a crisis of epidemic proportion (Moyers and Evans 1993; Raloff 1993). However, the efforts of organized groups of advocates and activists extend beyond the matter of calling attention to incidence and mortality rates for breast cancer. Women have responded to the epidemic in a variety of ways, from writing about their own experiences of diagnosis and treatment, to organizing local support groups for cancer patients, to establishing grassroots organizations to call for changes in current standards of prevention and treatment for breast cancer[2] (Marshall 1993; Love 1993; Ms. 1993; McCoy et al. 1992; Solomon 1992; National Women's Health Network 1993; Boston Women's Health Collective 1992).

Not all of those who have responded to the problem of breast cancer would refer to their efforts as "activism." For some, this term carries political connotations that inadequately describe their endeavors to secure better access to informed health care or support services for women newly diagnosed with cancer. Those whose primary concern is to develop client-centered health care—whether consumers or providers—frequently use the term "advocacy," rather than activism, to describe their efforts on behalf of women with cancer.

There is a wide range of meaning to "activism" in the breast cancer movement as in other movements. Activism describes everything from efforts to work with clinicians, researchers, and hospital administrators to build more comprehensive programs of prevention and treatment for particular diseases; to lobbying state and federal legislators for changes in public policy regarding these diseases or appropriations for research and treatment programs; to more confrontative tactics such as public demonstrations and civil disobedience whose purpose is to wrest control over the provision of health care from a system of care and research that is regarded as unresponsive. These latter activities have been utilized in some organized efforts related to AIDS; activities of breast cancer activists, for the most part, have taken more conventional forms.

Nonetheless, there is anger in the breast cancer movement. For women whose experiences include deferred diagnoses or misdiagnoses about breast cancer and the dilemma of cancer treatments that offer negligible promise, it is not enough to reform the present system. Expanding access to state-of-the-art care means little when current treatment regimens are debilitating and ultimately ineffective—a point that is given much credence by clinicians and health care researchers

(*Lancet* 1993; Hellman 1993; Ganz 1992). From these perspectives, theories of breast cancer must be reenvisioned and methods of treatment improved, and it is to these ends that activists work (Love 1993).

Activists and advocates within the breast cancer movement agree on these points: There are too many women diagnosed with breast cancer, and there are too few effective treatments. Although many cancer survivors, activists, and advocates speak of the desirability of a "cure" for breast cancer, that is considered, at best, a remote prospect. Meanwhile, activists and advocates work to revise or reform current systems of care and to maintain their own fragile states of health in the process.

The Case For Health Care Activism

The remainder of this chapter analyzes the breast cancer movement, drawing on ongoing field research and interviews with cancer activists and advocates, including public testimony before the President's Cancer Panel (1992). Breast cancer activists offer researchers and policymakers a wealth of information about how communities and individuals operate in the context of life-threatening illnesses, as well as "patient" experience with and access to treatment.

Equally important, organized groups within the breast cancer movement actively seek collaborative relationships with researchers and policymakers. Some of these groups are no longer willing to tolerate polite indifference from the biomedical community. They have learned from the experiences of their own constituencies, as well as from activists in the AIDS movement, that some health care crises require action beyond that which researchers and policymakers are willing to take without pressure (Thompson 1992).

In sum, breast cancer activism offers a case study of how citizens have become informed, organized participants in their own health care. Such groups are powerful allies in the work of community-based coalitions for health care interventions. However, they bring a well-fashioned perspective on the problems of health and prescriptions for remedies that may clash and conflict with the perspectives held by other coalition members. This chapter also draws parallels between the breast cancer movement and other health care movements within Appalachia. It suggests avenues to follow in programs for cancer prevention and treatment in the region, recognizing at the same time that regional as well as rural-urban differences factor into health care strategies exercised by residents within and outside Appalachia. This chapter concludes, as do Chapters 8 and 9, with the observation that what is desirable or effective in Appalachian communities rests with grassroots organizations within the region.

As Chapter 5 attests, the history of Appalachia is filled with various projects of "enlightenment" and "uplift," organized by outsiders with vested interests in the mountains. The ultimate achievement of many of these undertakings was the degradation of the mountains and their inhabitants, who fought bitterly against such projects of disenfranchisement (Whisnant 1981; Waller 1988). This chapter does not illustrate the need for external intervention in another form, the breast cancer movement; rather, it points out another set of health care activists whose concerns are similar to those of other health care movements in the mountains and who present important groups for community-based coalitions concerned with cancer to deal with.

Cancer Survivors and Activists

Although individuals participating in grassroots cancer organizations run the gamut in terms of prior experience with feminism and other social movements, the origins of cancer activism as a national phenomenon can be traced back to the 1970s and the development of the women's health movement. The principal concern of the women's health movement

was to establish access for all to gynecological and obstetrical care that was both medically sound and sensitive to women's needs (Cambridge Documentary Films 1973).

In the 1970s, the struggle to make birth control safe and to legalize abortion made clear the differences between the medical services available to poor women and women of color and those available to women of financial means (Seaman and Seaman 1978; Gordon 1974). Although this was a major problem, it was one that could be remedied through changes in existing programs and the establishment of women's health clinics to offer quality care to all, regardless of ability to pay (Boston Women's Health Collective 1992; Ruzek 1978; Lewin and Olesen 1985). At the same time, women in the burgeoning health movement began to examine critically the kind of training physicians received and the treatment they offered their patients and to present alternative models of health care that were more sensitive to women's needs and perspectives (Lewin and Olesen 1985; Ehrenreich 1978; Corea 1985; Scully 1980).

Related to the concerns of the women's health care movement, several women newly diagnosed with breast cancer wrote personally and profoundly about their encounters with the medical system and with the prospect of their mortality (Kushner 1975, 1984; Rollins 1976; Lorde 1980, 1988; Metzger 1981). All endeavored to make public the personal experience of coming to grips with the diagnosis of breast cancer and making decisions about treatment under high-pressure circumstances. For Rose Kushner, the effort to "go public" was coupled with her activities as an advocate for alternatives to what were then considered standard treatment for breast cancer: one-step surgical procedures—in which biopsy was coupled with mastectomy if the biopsy proved to be positive—and the Halsted or "radical" mastectomy in which the breast was removed along with the chest muscles and underlying lymph nodes from the area of the breast up to the collarbone (Kushner 1975, 1984). Not only were such procedures frightening and mutilating, Kushner argued, but they also constituted poor medical treatment.

Poet Audre Lorde chronicled first the experience of surgical biopsy, then later her mastectomy and her decision not to "pass" by wearing a prosthesis to conceal the removal of her breast (Lorde 1980). Both Lorde and Deena Metzger wrote of the emotional as well as physical turmoil that followed diagnosis, and both wrote about the struggle to accept their bodies, postmastectomy—Metzger perhaps being better known for the photograph of a woman's torso with a tree of life emblazoned across the space where her breast had once been (Metzger 1981). Lorde wrote again, when diagnosed with metastatic breast cancer, of her decision to rely on unconventional cancer therapies and of facing death (Lorde 1988).

The power of these narratives is derived not only from their emotional content but also from their frank and detailed discussions of the medical procedures involved in screening, diagnosis, and treatment of various stages and types of breast cancer. They provided new and different perspectives on cancer and its clinical treatment. As with the women's health movement in general, the narratives of women fighting breast cancer were based on the assumption that providing information to women enabled them to make better decisions about possible treatment and thus improved their chances for recovery (Bruning 1985).

For other women, these narrative accounts provided more than self-help guides. The testimonies of cancer survivors served as rallying cries urging women to declare breast cancer a social problem as well as a personal tragedy (Lorde 1980, 1988; White 1990; Butler and Rosenblum 1991; Brady 1991). The women's health movement has witnessed the writing of additional individual accounts and informational texts, while the numbers of new diagnoses and deaths from breast cancer continue to rise (White 1990; Butler and Rosenblum

1991; Brady 1991; Stocker 1991; Wilber and Wilber 1991; Wadler 1992; Brinker and Harris 1990; Kelly 1991; Love and Lindsey 1991).

In addition to the creation of a collective authorship and readership around the issue of breast cancer, women have come together through support groups for cancer patients to discuss the difficulties they encountered in the aftermath of diagnosis and treatment. Although the emotional crises of coping with disability and the prospect of one's death provided much impetus for such discussions, conversations also turned to recommendations—born of experience—for ways to deal with chemotherapy and how to consult physicians for second opinions. Patient advocates began meeting in other ways to talk about the need for better information and services geared to the specific problems of women with cancer as well as the urgent need for innovative research on the origins and treatment of reproductive cancers. Thus, the breast cancer movement was born.

We Will No Longer Die Quietly

Across the country, as the 1980s gave way to the 1990s, cancer survivors, advocates, and activists have formed a variety of grassroots organizations that go beyond self-help to address other aspects of the crisis of breast cancer. Whereas some groups focus on breast cancer exclusively, others deal with reproductive cancers or the wider array of health problems to which women, in particular, are susceptible. However, even in the latter organizations, breast cancer remains a point of concentration for programmatic efforts because of the enormous number of women newly diagnosed or experiencing recurrent breast cancer.

For grassroots groups centered around breast cancer, there are divisions between organizations whose primary objective is to make support services readily available to women diagnosed with breast cancer and those organizations involved in changing public policies and perceptions regarding this disease. Table 1 presents a list of support services offered to women with breast cancer. Still other groups serve particular populations of women—poor women, women who are underinsured or uninsured, lesbians, rural women, and women of color—who have limited access to basic health care, in addition to few facilities that are equipped to detect and treat breast cancer. Finally, there are some advocacy groups that combine aspects of all the grassroot groups listed above in their statements of purpose (National Women's Health Network 1993).

One characteristic that distinguishes grassroots advocacy groups from nonprofit organizations such as the American Cancer Society is that when they offer support services they do so as part of the community affected by cancer. Such grassroots organizations begin with personal knowledge of the limited resources available to women fighting cancer and a recognition of the need for alternatives to existing systems of health care and social support in the community. The anger and conflict that marked the pages of Lorde's and Kushner's personal histories are reflected in the efforts of cancer survivors to develop community-based programs that replace the idea of technology-based cures with human, culturally sensitive assistance. Thus, grassroots breast cancer groups deal with the legal crises that befall cancer patients by offering workshops and referral services for problems in securing disability or insurance coverage, for example, while simultaneously pressing policymakers for changes in the legislation that addresses these issues.

Breast cancer survivors and advocates have learned from the AIDS movement about the importance of challenging existing research priorities and resource allocations. Breast cancer groups have created political strength sufficient to attract the attention of legislators and members of the scientific community to these matters through collective efforts, as members of the National Breast Cancer

TABLE 1

Support services for women with breast cancer

Breast Reconstruction

Care
- Hospice
- Postoperative care (home and hospital)

Counseling *(peer and professional)*

Complementary Therapies
(alternative and adjunctive)

Detection
- Breast screening and mammography

Education and Information
- Breast self-examination training
- Classes in relaxation, pain management, and biofeedback
- Information hotline
- Lecture series
- Library resources:
  —scientific journals, informational guides, and writings for and by cancer patients
- Newsletters
- Physicians Data Query (PDQ)
- Political advocacy

Legal Services

Nutrition
- Information
- Services

Patient-Centered Medicine

Prosthesis

Referral Service
- Second opinions
- Specialists

Support Group
- Bereavement
- Friends and family
- Peer
- Professional

Specialized Treatment
- Bone marrow transplant and information
- Clinical trials
- Lymphedema services
- New treatments and investigative drugs
- Physical rehabilitation
- Tumor board

Volunteer Assistance
- Child care
- Housework
- Meal preparation and delivery
- Transportation

Wigs

Source: Adapted from Shopland and Massey 1990, p. 55.

Coalition (NBCC), the National Alliance of Breast Cancer Organizations, and other state and regional coalitions.

In 1992, for example, NBCC and its members successfully lobbied Congress to approve a budget of more than $400 million for breast cancer research, an almost threefold increase from the federal budget for breast cancer research of the previous year (Love 1993; Ms. 1993). These efforts even required rebutting criticism of their success (*Nature* 1992; Culton 1992). For example, when the *New York Times* criticized NBCC's success, NBCC president Frances Visco responded:

> *In bemoaning the manipulation of the budget process, the editorial writer profoundly missed the point. The bureaucratic games that determine how much money goes towards research are deadly serious to us, the women with breast cancer. We have not been outrageous—we have not yet bared our chests to show our scars or pelted Congress with prostheses—not yet. But*

we will no longer adhere to a courtesy that costs us our lives. (F. Visco, personal communication, November 16, 1992)

These were more than angry words. In the same letter, Visco gave notice of "a revolution" staged by and for the "more than 2.8 million American women [who] have breast cancer."

Some breast cancer activists emulated the "treatment activism" used by groups addressing HIV/AIDS. When requests for more and better treatments yielded little response, AIDS activists resorted to underground laboratories and pipelines and confrontational strategies as ways of expanding the access of desperately ill people to state-of-the-art health care (Shilts 1987). At the same time, treatment activists helped create a more interactive form of scientific research, which features community advisory boards for research programs, parallel tracks or expanded access to clinical trials, and compassionate release of experimental treatments with demonstrated therapeutic efficacy. In so doing, AIDS activists gained greater participation in decision making about AIDS research and treatment, increased respect from some portions of the medical community, and access to more effective treatments for HIV (Wachter 1992; Cotton 1990; Merigan 1990). The path to these consequences remains filled with conflicts over the protection of the public from unproven treatments on the one hand and access to potentially effective treatments on the other.

In a similar spirit, breast cancer activists have been working to create community liaisons with cancer centers and university research programs as well as to have women with breast cancer sit on commissions that review proposals for clinical research (Love 1993; President's Cancer Panel 1993). Breast cancer activists want to facilitate access to improved treatment and prevention. They want state-of-the-art treatment to be made available to all women with breast cancer, not simply to those with sufficient financial means. Access to quality care will be fully achieved through overall reform of the health care system—an objective that breast cancer activists endorse. In the short term, concern over access translates into proposals for (1) the expansion of clinical trials for women with breast cancer to include populations currently underserved, including women with advanced disease and young women often excluded for reasons of liability; (2) better systems for informing breast cancer patients of treatment alternatives, including clinical trials; and (3) more extensive physician education on promising treatments and their implications for current standards of care (President's Cancer Panel 1992).

Breast cancer and treatment activists advocate for treatments that might sustain women for progressively longer periods of disease-free survival and provide for a better quality of life. In the tradition of Rose Kushner, treatment activists call for new drugs to be tested and for treatments that are *less* toxic, *less* devastating, and *more* effective. They challenge the use of the word "cure" by clinicians and researchers to describe treatment options that offer the prospect of 5-year periods of disease-free survival. Inasmuch as mortality rates have not improved in the past four decades, describing periods of survival as "cures," say treatment activists, only serves to mask the gravity of the problem for individual women with breast cancer and for a society beset by a disease still poorly understood (Kelsey and Gammon 1991; *Lancet* 1993).

Finally, breast cancer activists have called for research into the prevention of breast cancer as well as its treatment. In place of the current emphasis on "secondary prevention" through early detection, cancer activists have advocated for research that moves beyond simplistic assessments of environmental factors and other possible causes of breast cancer (Krieger 1989; Jones and Powles 1991; Raloff 1993). Such research, advocates believe, complements but does not replace the need for

community-based programs to screen women for breast cancer and the need for more accurate and less invasive methods of detection, such as the development of tumor markers or blood tests (President's Cancer Panel 1992).

Health Care Activism and Community Initiatives in Appalachia

Many lessons can be learned from the breast cancer movement, not the least of which is that people affected by diseases such as breast cancer can engage successfully in organized discussions and actions concerning health problems and strategies for contending with these problems (Riessman et al. 1992; Gamson 1991; Friedman and McAdam 1992). The knowledge base and experiences of these activists and advocates are different from those within the health care system. As Chapter 3 points out, what health professionals describe as fatalism may be a pragmatic assessment by potential clients of their risk for a given disease or the likelihood of obtaining good care (meaning culturally as well as technically appropriate care) (Millon-Underwood et al. 1993).

By contrast, both breast cancer and AIDS activism illustrate myriad ways that members of communities mobilize to respond to problems that jeopardize their health and well-being (President's Cancer Panel 1992; Ruzek 1978; White 1990; Brady 1991; Freudenberg and Trinidad 1992; Schoepf 1992; Krieger and Margo 1990). Community groups confront not only the problems experienced by individuals diagnosed with life-threatening diseases such as breast cancer or HIV/AIDS but also the social consequences of illness: loss of income and other crucial resources caused by the disability of those who were formerly wage earners; reorganization of systems of care around those who are ill, rather than young and elderly members of households; and fragmentation of social networks by illness, death, or overburdening of people who were once active members, to mention some of the most obvious repercussions. At the same time, communities are responding to problems that more broadly reflect poverty, racism, sexism, homophobia, and the vicissitudes of life in the late 20th century (White 1990; Brady 1991; Stocker 1991; Freudenberg and Trinidad 1992; Krieger and Margo 1990; Ankrah 1991; Fee and Fox 1992; Farmer 1992; Herdt and Lindenbaum 1992; ACT UP/NY Women and AIDS Book Group 1990). Communities reflect specific intersections of geographic or regional orientation and social concerns, among which health care crises such as HIV/AIDS or cancer figure prominently.

For the most part, communities in Appalachia have approached issues of illness and health care through the arena of labor, in relation to the rights of workers (and their families) to health care and compensation for illnesses, injuries, or deaths related to occupation. Thus, for example, coalmining communities in Appalachia organized the black lung movement—at one point, confronting even the United Mine Workers of America (UMWA) as well as the coal industry, the medical profession, and the government. The aim of the black lung movement was to secure disability benefits as well as medical treatment for miners who developed chronic pulmonary disease as a result of their exposure to coal dust (Judkins 1986, 1993; Smith 1987). Concerns about access to health care and disability compensation for retired as well as active coal miners similarly have fueled the activities of UMWA, as was the case in the 1989 strike against the Pittston Coal Company (Giardina 1989; Couto 1993).

Similarly, with respect to the issue of pollution, grassroots organizations have addressed the deterioration of land, air, and water in Appalachia as both an economic matter and a health concern. These environmental and economic problems pertain especially to industries regarded as important contributors to household and regional economies but

that nonetheless threaten the health of their employees and contaminate local environments through illegal methods for handling toxic or waste materials. Connie White, past president of Save Our Cumberland Mountains (SOCM), a citizen organization formed in 1971 in eastern Tennessee, observed the impact of environmental contamination on her own community in terms reminiscent of the anger and frustration of other health care critics.

> *Living downstream [from the factories in Oak Ridge, Tennessee], where even the municipal water system at Kingston has had to be turned off at times because of mercury spills, I saw my father and four out of five of his sisters who stayed in Roane County get cancer. I saw the Oak Ridge plants fight to try to continue to exempt themselves from the water and air quality regulations that help protect us, to literally say they are above the law. But we also know from our own experience that these Oak Ridge jobs sometimes are the only chance that we as ordinary people have to make a decent living, to have good health insurance which can literally make the difference between life and death, and have a retirement where we can live with the dignity that is so well deserved (White 1993, p. 6).*

In some instances, community organizations operated as coalitions uniting workers and area residents in opposition to industries that violate environmental and safety regulations, as happened in the instance of a long but ultimately successful struggle to decommission a hazardous waste processing facility in western North Carolina (Anglin 1986). However, as White (1993) noted, the challenge for organizations such as SOCM is to balance the need for "a decent living" with local and regional policies that safeguard the environment and the health of people who live "downstream."

Beyond questions of whether and how grassroots groups and labor unions have succeeded in efforts to hold industries accountable to local communities is a much larger issue: that is, that health and illness are viewed by some groups in Appalachia as political matters, just as they are considered political concerns by health care activists and advocates elsewhere. Rather than fatalism or acquiescence, these efforts are sophisticated analyses and organized efforts for change, as Chapter 5 in this monograph would lead us to expect.

Building Health Care Coalitions

If labor and other community activists in Appalachia have treated the issue of health care as a political and economic concern, some health care providers in the region have considered economic, social, cultural, and other factors in addressing the needs of their constituencies. This is perhaps most evident in parts of rural Appalachia where mountain passes and miles of highway mark the distance between homes and health care clinics or the nearest factory and there is no such thing as public transportation. It is not just that financial means, work schedules, availability of child care or transportation, and physical distance make it more or less possible for area residents to use the resources of health departments, clinics, and hospitals. Equally important determinants of "accessibility" are the ways that health care programs are structured and the relationships between the providers of health care and the communities in which their programs are located.

This point is underscored by anthropological field research interviews with providers and administrators of health care programs in two western North Carolina counties.[3] For health care to be truly accessible to people in western North Carolina, providers and administrators argued, it must be responsive to the local communities in the spirit as well as the format of programs offered by health departments, hospitals, or freestanding clinics.

For example, one nurse from a well-regarded

county health department spoke simultaneously about what it had been like to grow up and to raise her own children in that county and about the evolution of the health department, with which she had been associated since its inception. She combined her education at a nationally recognized university and her reliance on the terminology of public health with her knowledge of the area. This nurse spoke about clinics and home health visits as someone who lived in the community, not simply as one who served it. The women she saw in maternal and child health clinics were people she had known for years and whom she treated as long-term acquaintances as well as patients. This increased their reason to trust her.

Similar themes were reflected in interviews with other health care providers and administrators of well-attended, popular programs. Providers and administrators involved in a range of health care services and clinics held in common a conviction that effective "community outreach" was based on the informal and formal ties they forged with other county residents as well as their own commitment to these communities. To state the point differently, it was in the spirit of advocacy, rather than professional distance, that successful health care programs were offered by providers and received by constituencies in the mountains.

A crucial dimension of organizing successful community-based health coalitions, such as those supported by the Appalachia Leadership Initiative on Cancer, is the collaboration of health and community service professionals with locally based health care advocates and activists. The insights and concerns of health care activists and advocates outlined in this chapter suggest the problems and prospects of such collaboration. Some recommendations that are based on the testimony of cancer survivors and advocates to the President's Cancer Panel, Special Commission on Breast Cancer, offer specific direction to community-based health care coalitions such as those organized through ALIC (President's Cancer Panel 1992).

► Engage self-defined community leaders, male and female, in outreach initiatives. Do not rely solely on professionals (even if local residents) for programmatic efforts.

► Listen to the advice of community leaders and members about the problems they recognize, and build a collective approach, not a unilateral agenda.

► Locate state and regional grassroots health activists and organizations. Read their newsletters and consult with them about community-based health initiatives.

► Locate grassroots organizations in the area, which may or may not directly pertain to health care, and consult them on the general concerns of local communities in the mountains.

► Address the problems of rural communities: lack of transportation, underfunded local health care programs, and inaccessibility of specialized care caused by geographic distance from regional centers and the cost of medical services.

► Address the burden placed on the working poor in using health facilities: finding child care and time away from wage-earning activities to come to public health programs during operating hours; waiting for screening programs often available only on a weekly or monthly basis and for which there is a backlog of cases; and coping with competing demands to obtain health care and to provide care for other household members who are ill.

► Call on local institutions as resources in organizing educational forums on the initiative. The material presented must be sensitive to the norms and practices of local communities.

► Develop educational materials for distribution to local health care providers and community institutions. Where possible, the materials should be written in collaboration with representatives from the region.

► Expend resources to make screening technologies and treatment programs more readily available to local communities. Provide training for local health care providers so that they are aware of current standards of treatment for cancer.

► Use ALIC as an opportunity to explore environmental cofactors in the etiology of cancer. Develop a format to gather intensive epidemiological data on local risk factors and cancer patterns.

Far from being exhaustive, this list represents some of the demands routinely made by health care activists. They also represent good community health education practice. In the present context, they are proposed as recommendations for organizing programs for cancer prevention and treatment that meet the needs of communities in Appalachia and foster effective collaboration between health care researchers and providers, the people they wish to serve, and groups of people who have already taken measures to meet their own needs.

Notes

1. The research on which this chapter is based was funded by the National Institute on Aging, Training Grant No. T32 AG00045, through the Medical Anthropology Program, University of California, San Francisco.

2. For purposes of simplicity, this chapter refers primarily to women in speaking of breast cancer survivors and activists. However, it should be noted that although women constitute almost the entirety of the population with breast cancer, men also have been diagnosed with breast cancer and should not be overlooked. According to the National Cancer Institute, the 1989 mortality rate for breast cancer in men was 0.3 per 100,000 compared with 27.5 per 100,000 for breast cancer in women (Harris et al. 1992). In addition, grassroots organizations dealing with breast cancer call on men as cancer survivors and relatives or supporters of women with breast cancer to work as allies and activists. Nonetheless, the leadership and membership of the grassroots movement is, for the most part, composed of women.

3. This research was conducted from 1981 to 1983, supplemented by more recent conversations with health care providers as well as additional anthropological field research from 1987 to 1988 on factory workers in Appalachia.

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CHAPTER 10

Action Steps

1. Listen to those suffering from cancer to gain personal knowledge of the limited resources available to them and the need for alternatives to the present system of health care and social support.

2. Create community liaisons with cancer centers and university research programs to better explain local research needs and resources.

3. Recruit individuals with cancer to sit on various advisory boards and commissions that review proposals for cancer programs and clinical research.

4. Evaluate the structure of local health care programs and the conduct of health care providers by interviewing cancer patients and those at risk for cancer.

5. Incorporate into local coalitions the members, activities, and advice of other health advocacy groups. Review the recommendations that breast cancer groups made to the President's Cancer Panel that are summarized in the conclusion of this chapter.

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SECTION III

Sowing the Seeds

Sowing the Seeds

In the fall of 1992, the Appalachia Leadership Initiative on Cancer (ALIC) set out to learn how to help empower residents of Appalachia to prevent and control cancer. The four ALIC projects (Northern, North Central, Central Highlands, and Southern) together target nearly 80 percent of the Appalachian region and will develop projects in 11 of the 13 Appalachian states. A map showing the four project areas is presented in Figure 1.

The differences among the geographic areas to be served by each of the four ALIC projects include the mix of urban and rural populations. ALIC projects initially will focus on residents in rural areas, especially those who lack resources, are medically underserved, and are at great risk for cancer as indicated by measures of income, age, and education, as Chapter 7 explains. As shown in Table 1, the number of rural Appalachian counties within each ALIC project ranges from a low of 32 counties (or 12 percent of all rural counties in Appalachia) for the Northern Appalachia Leadership Initiative on Cancer (NALIC) project to a high of 83 counties (or 31 percent of Appalachia's rural counties) for the Central Highlands Appalachia Leadership Initiative on Cancer (CHALIC) project. The four ALIC projects will serve 218 rural counties or 82 percent of all rural counties in the region.

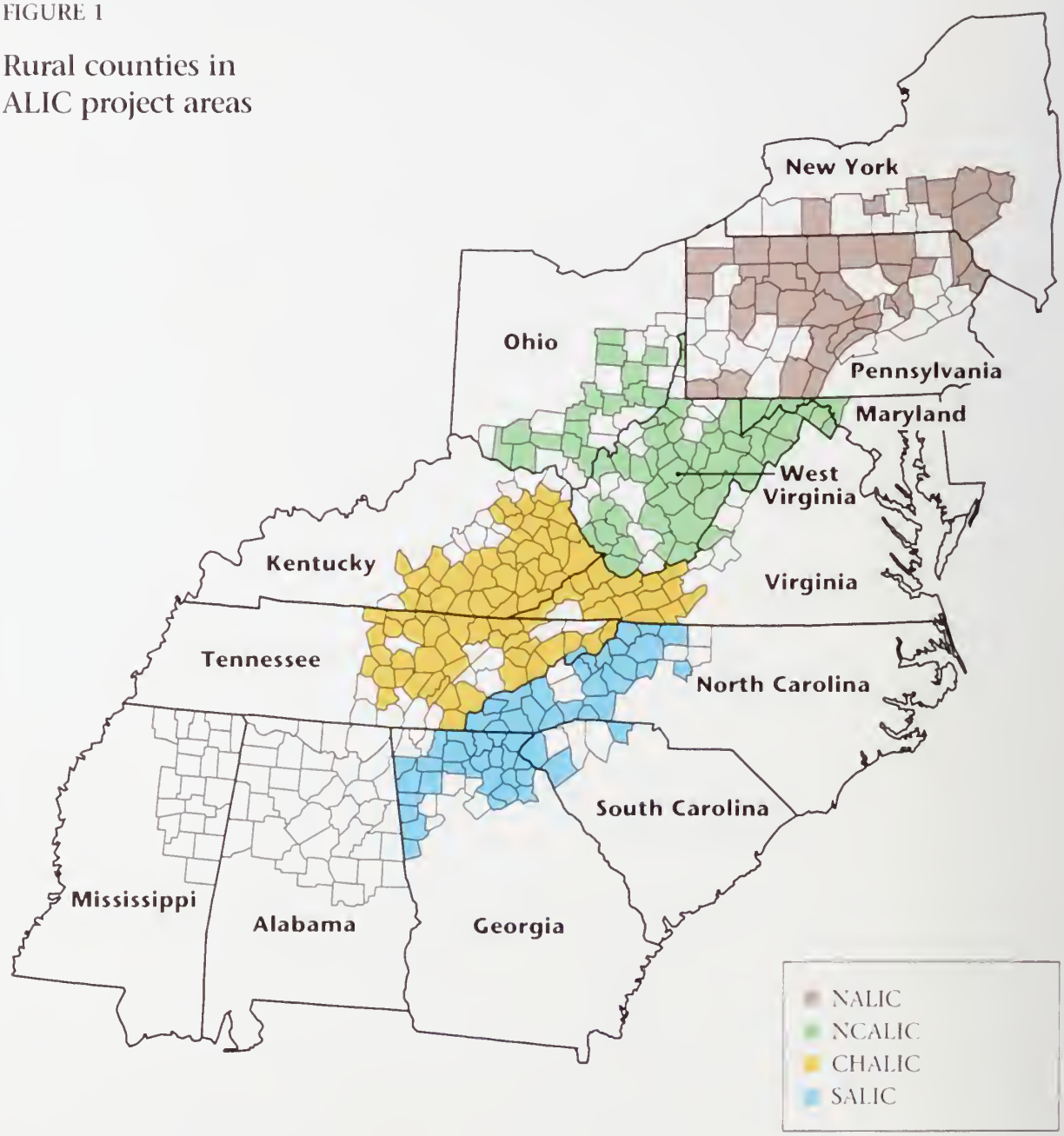
Much already has been learned, in general, about this task of ALIC, as Sections I and II explain. Section III describes ALIC's plans to develop coalitions that will use existing resources and state-of-the-art approaches to improve cancer prevention and control efforts. ALIC coalitions, in turn, will promote system changes in communities and will facilitate the development, implementation, maintenance, and evaluation of long-range, comprehensive, multidisciplinary, and communitywide cancer prevention and control intervention programs.

The four chapters of Section III provide specific information on each of the ALIC projects. The emphasis on rural areas and on both the supply and demand aspects of the cancer problem distinguishes ALIC from preceding community change efforts by the National Cancer Institute (NCI). ALIC also will extend previous health interventions by community-based coalitions by focusing on a region with diverse groups rather than on a single racial or ethnic group regardless of its place of residence.

The chapters of this section also explain that the ALIC program with its four projects attempts to move beyond previous, similar efforts. As described in Chapters 3 and 7, knowledge of cancer incidence, mortality, and survival in Appalachia and among the different socioeconomic groups who live there is incomplete; hence, ALIC's objectives include stimulating cancer prevention and control data collection and research in the region. Evaluation components to assess the effectiveness of the initiative and its individual pro-

FIGURE 1

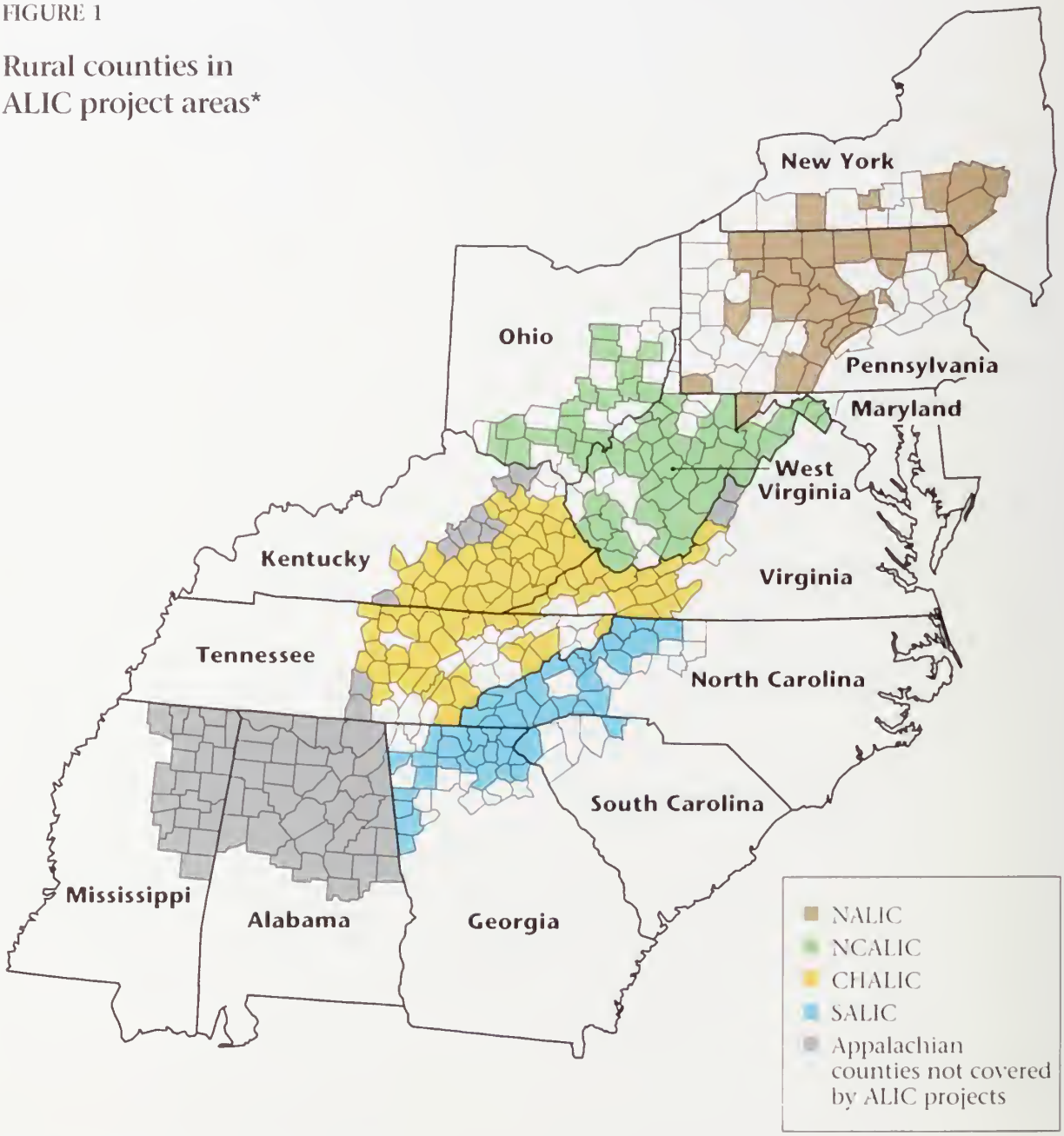
Rural counties in ALIC project areas



jects will provide valuable information on approaches to cancer prevention and control by community-based coalitions that will extend and perhaps sharpen the lessons laid out in Chapters 8, 9, and 10. In relating the strategies that the four individual ALIC projects will use to achieve the goals and objectives of ALIC, Section III necessarily focuses on the initial planning and coordination phase of the projects, which have just completed their first year of operation. The "nuts and bolts" character of Section III permits readers to determine how each ALIC project has incorporated the insights provided in Sections I and II. Time will reveal how well each project incorporates those insights. Likewise, the

FIGURE 1

Rural counties in ALIC project areas*



**See Appendix F for definition of rural county*

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TABLE 1

Rural Appalachian counties served by ALIC projects*

ALIC Project	Number of Rural Counties	Percent of Appalachian Rural Counties
NALIC	32	12
NCALIC	57	21
CHALIC	83	31
SALIC	46	17
Project Totals	218	82†
Appalachia Total	266	100

**See Appendix F for definition of rural county.*

†*Due to rounding.*

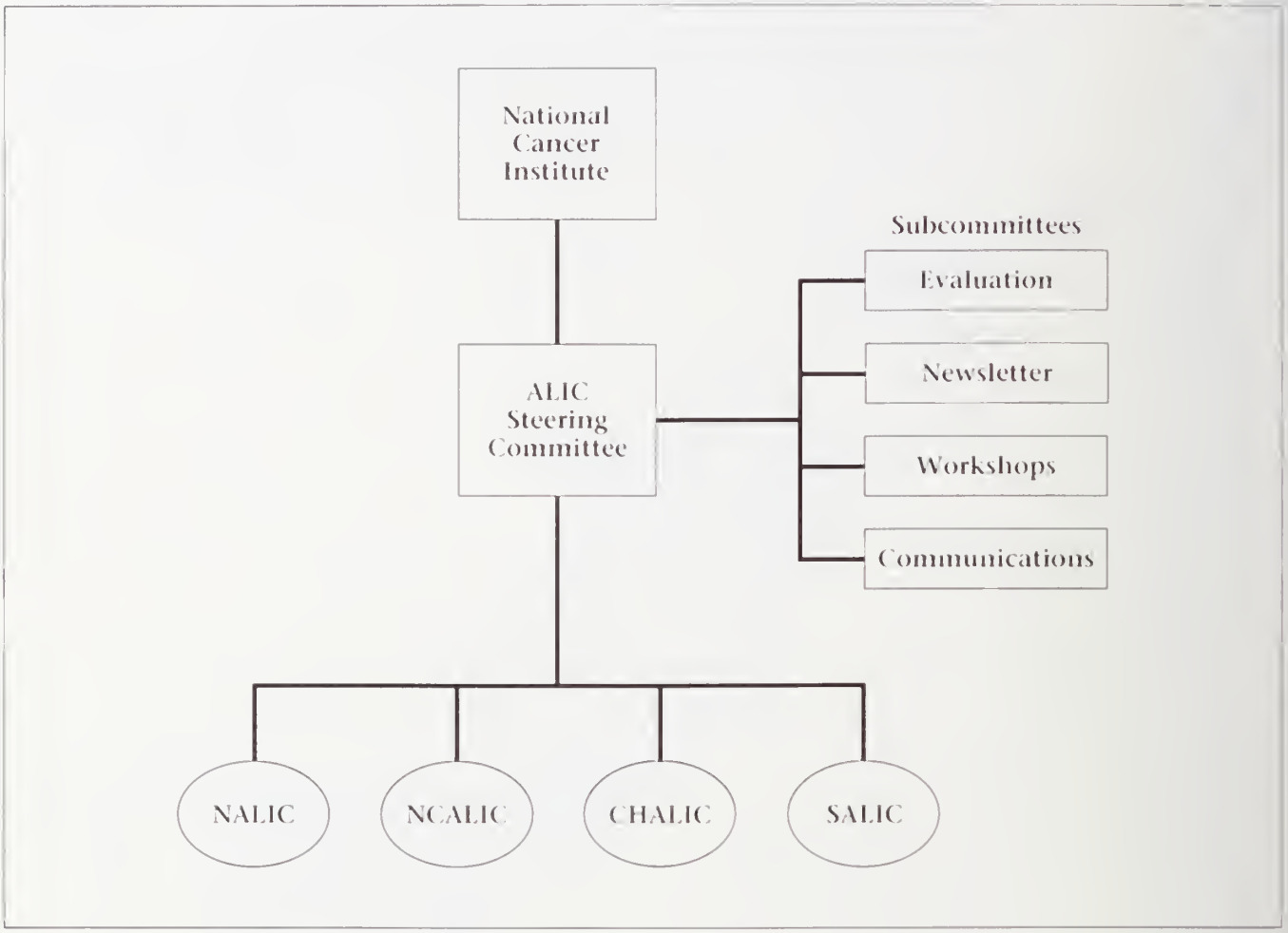
experience of each ALIC project over the next few years will provide insights that can be shared with programs that follow.

Before each project is discussed, some background about the ALIC program is useful. Under a cooperative agreement, a partnership has been established between each ALIC project and NCI. The role of NCI is to provide program advice and technical assistance chiefly through NCI's ALIC program director. Each of the four projects is responsible for the planning, direction, and execution of its respective activities. Institutions that receive NCI awards will organize and initially support area offices that will be staffed by full-time community coordinators and relevant support staff. The coordinators will facilitate the establishment of coalitions within the project areas and interact with them. An ALIC steering committee, composed of the NCI ALIC program director as well as project staff (principal investigators and project managers) from the four projects, has been established to provide guidance, coordination, and support for program activities and to identify program needs and resources. For example, the steering committee has already identified the need for workshops on community development and cultural issues in Appalachia, evaluation, and development of project materials and messages for special populations such as low-literacy groups. Figure 2 illustrates the organizational arrangement of ALIC.This outreach initiative will advance through two broad, overlapping phases.

▶ Phase 1, lasting 1 year, includes area-wide planning and coordination of outreach resources and contacts. Activities include planning strategies for identifying and recruiting community leaders and developing and supporting community coalitions within defined geographic areas. This phase also will focus on developing specific plans for evaluation, project implementation, and management as well as producing a plan for developing and disseminating project messages, materials, and products.

▶ Phase 2 will begin during the second year of the projects. Implementation, evaluation, and documentation of outreach activities will be initiated according to the comprehensive strategies and time schedule developed in

Figure 2. Organizational arrangement of the Appalachian Leadership Initiative on Cancer



Phase 1. Progress will be measured by established milestones. The third, fourth, and fifth years are to be continuations of the activities created in the first and second years. Special emphasis on data analysis and the dissemination of project findings will occur in the fifth year.

In their applications for the ALIC cooperative agreement awards, the four successful projects outlined preliminary strategies for meeting the goals and objectives of the initiative. As the projects conducted their first year of planning and coordination, 1992-1993, they refined and expanded those initial schemes. The approaches described in the chapters that follow are still in formation and will change according to input from advisory committees, needs assessments, coalition members, focus groups, process evaluations, and other sources of feedback. As the projects learn how their contexts (which were developed in the general terms described in Sections I and II) affect their work, they will undoubtedly make additional adjustments.

Each of this section's chapters has a similar format and examines each ALIC project for the same elements. Thus, the chapters explain the institutional actors for each project; the populations to be served; common characteristics of each project's area; the incidence and risks of cancer in the four areas; plans to mobilize leaders, organizations, and communities; and the coalition building blocks of each project. In addition, the chapters examine how each project plans to develop a network of coalitions, the development and dissemination of intervention programs and strategies, project evaluation plans, and initial

planning issues based on early experiences. Taken together, these elements describe the specific methods the projects will use to bring about change and the difference they intend to make.

The enthusiasm and ambitious intentions of the ALIC program and projects are tempered with knowledge that some things change slowly and imperceptibly. Mountains are worn down by millennia of wind, rain, and snow. Rivers gradually carve wider, deeper, or new channels over centuries of traveling to the ocean. Other changes happen more rapidly, sometimes bringing disaster, dislocation, or other hardship. Appalachians, especially rural Appalachians, are familiar with both kinds of change. Many still live in the mountains or valleys where their families settled generations ago. Many have witnessed changes that have transformed and sometimes disrupted lives in their communities. The industrialization of certain areas in the region and later the closing of factories, the building of waste treatment plants, or natural disasters such as floods and blizzards have forced Appalachians to cope with abrupt and often threatening changes in their lives. The resourcefulness, cooperation, and tenacity with which they have addressed such challenges have contributed slowly to the development of alliances, often informal and almost imperceptible to those new to the region, for either resisting or promoting change. The chapters of this section examine how ALIC intends to build on all these traditions to develop strategies and practices that will influence behaviors and systems in ways that ultimately will improve cancer prevention and control in the region.

The populations targeted by each project differ in ways that require different outreach and educational strategies. The size of the population, age of residents, health status, access to and utilization of health services, educational level, degree of rural character, and many other factors offer each project a different starting point for its work. Similarly, the areas to be served differ in the rates and forms of cancer and related cancer risks. In addition, the various counties within each project area differ by these same sorts of factors and require different starting points.

Two projects, NALIC and Southern Appalachia Leadership Initiative on Cancer (SALIC), share an institutional context with the Cooperative Extension Service; the other two, North Central Appalachia Leadership Initiative on Cancer (NCALIC) and CHALIC, are rooted in cancer centers within large university medical centers. These different backgrounds offer each set of projects differing starting points. The extension-related projects start with broad experience in program development and delivery at the local level and representatives in every county. The projects rooted in cancer centers start with knowledge of the resources and information related to cancer prevention and control.

Despite their differences, the four projects have common features. Each is working toward a program of cancer prevention and control that will develop and support projects involving both lay and professional community leaders as members of community-based coalitions. Each project is responding to the particular needs of its population and the social and economic conditions in the region, beginning with its own perception of the area, the people to be served, and the needs to be addressed. Each project has a primary institutional network with which it is familiar, yet each has incorporated less familiar actors into its coalition. This section provides a summary of the starting points of each of ALIC's four projects. We turn now to the specific goals and objectives of each ALIC project and to the specific plans each will use to attain them.

CHAPTER 11

Northern Appalachia Leadership Initiative on Cancer

Audrey N. Maretzki, Ann J. Ward, and Gale Harris

Institutional Context

The Cooperative Extension Service at the Pennsylvania State University (Penn State) in University Park, Pennsylvania, received an award to implement the Northern Appalachia Leadership Initiative on Cancer (NALIC) project. In association with the Cooperative Extension Service (CES) of Maryland at the University of Maryland, the Cornell Cooperative Extension Service at Cornell University in New York, and the Pennsylvania, Maryland, and New York divisions of the American Cancer Society (ACS), the Penn State project will target all 69 counties in the Northern Appalachian region.

The Cooperative Extension Service of the U.S. Department of Agriculture (USDA) is a land-grant university-based educational system established in 1914 to provide technical assistance; disseminate research-based information on agriculture and family life, including health; and support the development of the nation's youth through the 4-H program. CES conducts nonformal educational programs in all 3,150 counties across the United States. The cooperatively funded system is financed jointly by federal, state, and county money and has concentrated historically on reaching residents of rural communities. Recently, CES has begun to focus educational efforts to members of the limited-resource population as well. The Limited Resource Audiences Committee of the Extension System-USDA (ES-USDA) has recommended that state extension programs target the socioeconomically disadvantaged audience by collaborating with other human service agencies (Limited Resource Audiences Committee 1991).

In addition, at the federal level, rural health care and safety have been given the highest priority for educational programming by CES in 1994. *Decisions for Health*, a report produced by the National Extension Health Agenda Task Force (1992), calls for "the development of a community-motivated process of decision making that enables urban and rural communities to select health-related issues and develop collaborative solutions."

The priorities of the Limited Resource Audiences Committee report of the ES-USDA and *Decisions for Health* state that rural initiatives need to provide a model for health education that has a rural orientation, promotes community assessments to determine areas of greatest need, increases coordination among agencies to reduce duplication of services, identifies an information network to address health issues, and disseminates health information in a culturally relevant manner.

At the county level, the CES has offices and staff in nearly every county in Maryland, New York, and Pennsylvania. To respond to federal initiatives, university specialists have developed programs for counties to implement or have developed educational programs for local

activities. Many of the programs related to health promotion and nutrition have focused on increasing the self-determination and well-being of rural residents (Wang 1979; Halpert and Sharp 1991; Cordes et al. 1978). Only recently have community efforts such as NALIC been developed to involve grassroots interests and health care providers in designing the content of programs to help make the community health decision-making process an integral part of community life.

The NALIC project will extend and adapt current activities of the extension services in Maryland, New York, and Pennsylvania, to address cancer prevention and control through a formal collaboration with ACS divisions in those states. The American Cancer Society is a community-based voluntary health organization dedicated to eliminating cancer as a major health problem by promoting cancer research, prevention, and detection programs and providing educational programs and treatment services. Recently, education and screening programs to serve socioeconomically disadvantaged people have been a major focus of ACS.

CES agents in Maryland, New York, and Pennsylvania have been working for many years in the area of cancer prevention and control, particularly with the county-based units of ACS. CES agents serve as volunteers with local ACS units, and ACS staff members often serve as CES volunteers. In many communities, both extension home economists and ACS unit executives serve on both local health and human service councils. These councils frequently undertake activities such as community health fairs that include cancer screening and education activities. In each of the three states, extension agents have a long history of working with ACS. For example, in Pennsylvania, one agent spent 20 years training women in breast self-examination techniques and educating them about cancer risk

reduction. In 5 years, this agent educated more than 4,000 men, women, and college students on cancer screening and prevention practices. In Maryland, CES and ACS have signed a formal memorandum of understanding to work cooperatively in the area of cancer education. Just recently, the Maryland CES also began another collaboration with ACS, local health departments, the University of Maryland at Baltimore, the University of Maryland at College Park, and the Maryland Department of Agriculture in a 5-A-Day promotion program targeting women who participate in the USDA's Special Supplemental Food Program for Women, Infants, and Children (WIC). In New York, nutrition and cancer education have long been promoted by extension nutrition specialists at Cornell University's Division of Nutritional Sciences.

With the long history of cooperation between CES and ACS, collaboration on the NALIC project was inevitable. In addition, because ACS has a major focus on the socioeconomically disadvantaged population, each state's divisions have organized a task force to address this issue. NALIC is seen as an opportunity to focus the work of county ACS staff and volunteers on the needs of the medically underserved residents of rural Appalachia.

Because illiteracy compounds the problem of reaching many rural Appalachians in the NALIC region, NALIC enlists the expertise of the Penn State Institute for the Study of Adult Literacy. This organization conducts research, provides staff development, and prepares educational programs to enhance the literacy competence of adults in the functional context of teaching vocational and life skills. Institute staff members have been involved with a number of health-related projects, and their expertise will complement the services available to NALIC through the literacy efforts of the Cancer Information Service.

Additional collaborators on the NALIC project include the M.S. Hershey Medical Center and the Pittsburgh Cancer Institute. The Hershey Medical Center is the site of the Penn State College of Medicine, an extensive training and research facility. Specialists in cancer care, education, and outreach, who are also members of the Central Pennsylvania Oncology Group (CPOG), are members of the NALIC project. CPOG promotes professional education and community outreach programs and conducts cancer research in many rural Pennsylvania counties. College of Medicine staff will provide resources to assess the process of building coalitions, to evaluate the project's effectiveness in attaining objectives, and to support the self-assessment activities of the coalitions.

The Pittsburgh Cancer Institute (PCI), designated by the National Cancer Institute (NCI) as a comprehensive cancer center, provides cancer information and referral services, cancer treatment, and patient care as well as psychological and educational services. In addition to performing research, PCI is actively involved in cancer prevention, early detection, and community outreach programs. On the NALIC project, the staff of PCI will be responsible for providing ACS and CES staff and volunteers with current information about cancer as well as programs and materials that address the prevention and early detection of the disease.

Populations to be Served

As shown in Figure 1 in the Introduction to Section III to this monograph, within the 69 counties targeted by NALIC in Maryland, New York, and Pennsylvania, 32 counties (46 percent) are classified as rural (Appendix F of this monograph). By this measure, NALIC is much less rural than other ALIC project areas; however, many counties within NALIC's project area, which are classified "urban" because of the presence of populous metropolitan centers, have large pockets of rural areas.

Despite the moderately good economic status compared with the rest of Appalachia, the overall NALIC area lost more than 200,000

people in total population from 1980 to 1990, all from Appalachian Pennsylvania. As in other areas of Appalachia, most of the population of the 69 NALIC counties is white—more than 95 percent according to the 1990 U.S. Census. African-American and Hispanic residents are located primarily in the urban areas. In general, literacy rates for the NALIC area are comparable to the national rate. However, rural areas have lower literacy rates than urban areas (Appendices A and B of this monograph).

Northern Appalachia is characterized by considerable European ethnic diversity. The immigrants from Ireland who came to escape the failure of the potato crop were joined by others from the British Isles and Western Europe. They in turn were joined by waves of immigrants from eastern, southern, and central Europe who came to work in the mines, mills, and factories of a region that had water power and nonrenewable mineral resources. The newer immigrants who worked in the mines lived in company towns whereas their compatriots working in the mills lived in company-built rowhouses. However, in each group, they built ethnic churches and joined ethnic social clubs, and their children usually married into the same ethnic group. Because these immigrant families were large, extended, and stable, ethnic identity remains strong in many parts of the region today; unemployment is high in part because families do not readily leave the area in search of employment.

Common Characteristics of NALIC Communities

A typical rural town or village in the area served by the Northern Appalachia Leadership Initiative on Cancer is economically dependent on an extractive industry, such as logging, or was once a coal company town. The population might be between 5,000 and 8,000, although many small hamlets of fewer than 1,000 inhabitants dot the area. The town has limited commercial life. Residents buy their groceries at a supermarket in a strip mall that draws patrons from several small towns. A gas station and a car repair shop serve as the congregating places for the men of the community. During the weekend, the busiest part of town will be the site of the weekly flea market where numerous families from many area communities come together to sell collectibles, tools, used clothing, and baked goods. At one time there would have been a doctor, a dentist, and a lawyer in the town, but the building that once housed their offices is now occupied by an insurance agency.

The community is likely to have at least two churches: a Roman Catholic church for the families that emigrated from southern and western Europe and a Protestant church (Baptist, Lutheran, United Church of Christ, Presbyterian, or Methodist) that serves primarily the families who came from the British Isles and the Protestant areas of western Europe.

The community may no longer be able to maintain its own elementary school, necessitating the busing of children to a regional consolidated school where the elementary, intermediate, and high schools are located on a single campus on the outskirts of a larger town. The community is likely to have an active volunteer fire department (VFD) that sponsors community activities such as athletic teams. The VFD ladies' auxiliary often organizes social events to raise money for purchasing fire-fighting equipment. Other centers of social activity may include a Veterans of Foreign Wars post, a Moose or Elk club, and perhaps an Odd Fellows hall or Masonic temple.

Farming also has been important in the area, but the interactions between the outlying farming community and town or village life is often limited to shopping or marketing visits on the weekends. Members of farming communities, including the Amish who live in this region, are relatively dispersed but

maintain connections through marketing, church, or school associations. Weekly livestock auctions also attract farmers and their families.

As suggested by the descriptions of these communities, NALIC will need to develop specific strategies for working with less affluent residents of rural towns who may belong to a variety of civic, fraternal, and religious organizations. The project also will need to develop strategies that specifically target the geographically isolated rural poor whose social network is likely to be an extended family that is linked to many other families in the immediate vicinity through marriage or through the social obligations that connect rural neighbors. The barriers to cancer control in Northern Appalachia include a poorly developed rural public transportation system and a lack of reliable private transportation for the rural poor.

Attitudes among certain residents of the region may pose additional barriers. For example, many older residents of rural Northern Appalachia are very conscious of their mortality. In some cases, they believe God grants the length of time they have on this earth, and they choose not to meddle with divine providence. Because they may believe that they are "saved," they are not particularly afraid of death. However, older people who are diagnosed with cancer may believe that they will die slowly and painfully and become a physical and financial burden to others in the process. This possibility may serve as a psychological barrier to early cancer detection particularly among women, who are traditionally the family caregivers rather than those who receive care. Men, on the other hand, may consider it unmasculine to participate in screening procedures, particularly for black lung (a disease of coal miners) or prostate cancer, or to follow a low-fat, high-fiber diet instead of a traditional diet of meat and potatoes. These cultural barriers may be exacerbated by lack of education, regular employment, and social mobility. However, people in Northern Appalachia also have a strong heritage of working together to overcome adversity.

Incidence and Risk of Cancer

This project will focus on the problem of reaching and educating a rural population concerning cancer risks, prevention, and control. Cancer incidence and mortality in Pennsylvania's Appalachian counties, as reported in the state cancer registry for 1988, are close to the statewide averages but with substantial variability across counties. For example, cancer incidence in Appalachian Pennsylvania averaged 417 per 100,000 for males (ranging from 229 to 576) and 361 per 100,000 for females (ranging from 157 to 428). Cancer mortality in Appalachian Pennsylvania averaged 222 per 100,000 for males (ranging from 102 to 273) and 143 per 100,000 for females (ranging from 99 to 170). The variability, in part, is caused by small populations of rural counties (see Chapter 3 this monograph), but it also may result from lifestyle or environmental differences.

In the northern region, Appalachian counties are not markedly different from non-Appalachian counties in either cancer incidence or mortality; however, Appalachian counties have an older population than that of the non-Appalachian counties.

Incidence and mortality for cancers of the breast, colon, lung, and cervix are of particular interest because of the large numbers of persons involved and because mortality for these cancers can be reduced through lifestyle changes and participation in early detection screening programs. The challenge to NALIC lies in bringing about such changes despite the social, economic, and demographic characteristics of the area. Although low-income rural populations require a similarity of approach across the region, differences exist within the region among farming, mining, and industry- or service-based communities.

The county-based CES and ACS organizations are well suited to carry out the education programs through county-based community coalition building.

Mobilizing Leaders

The NALIC project staff and participants realize that the success and sustainability of this cancer prevention and control program is dependent on the involvement of a broad spectrum of community members in the coalition's decision-making process. Within the counties involved in NALIC, CES agents and ACS unit executives will work together as a team to initiate the formation of local cancer coalitions. Alternatively, they may find an existing health or human services council under whose auspices they can conduct community cancer education and outreach. The CES/ACS team will identify individuals and groups within the community who are interested in working on cancer-related issues and can represent their community's health concerns. To recruit individuals who represent a diverse rural population, the ACS/CES team and core initiating committee will look for potential coalition members among a variety of community groups such as senior citizen centers, high school clubs, fraternal and service organizations, volunteer fire departments, craft clubs, church groups, and sports teams.

With the support of the ACS/CES team, the initiating committee will conduct a needs assessment of the community to identify the cancer concerns of the community, the county-specific levels of cancer incidence and mortality, the resources available in the community to provide a cancer training and outreach program, the history of cancer outreach activities in the community, and the areas of greatest social and economic need in the area. An assessment of this sort has been developed by the Pennsylvania Division, Inc., of the American Cancer Society and will be adapted for this project. This assessment also will help identify groups in the community that have a history of working successfully with rural, low-income residents as well as an interest in continuing this work. Individual representatives also may be identified as potential coalition members.

The success of NCI's Community Intervention Trial for Smoking Cessation (COMMIT) project (see Chapter 9) has influenced NALIC's approach to cancer prevention and control. Similar to COMMIT, the NALIC project is designed to provide a broader base for efforts to change high-risk behaviors by involving diverse individuals, groups, organizations, and institutions in coalition membership and program activities. Involving individuals from different walks of life who are in touch with their local communities is a way to promote ownership and greater participation in planned cancer prevention and control activities. More important, this community approach will encourage local institutions to integrate NALIC intervention strategies into their own program goals, enabling cancer prevention and control to become part of the communities' resources and services and, thus, to continue NALIC's efforts beyond the project's funding period.

The Building Blocks of Coalitions

For the past 20 years, CES has conducted a specially funded and highly successful program called the Expanded Food and Nutrition Education Program (EFNEP). Through this program, low-income youth and families with children are provided with free lessons on meal planning and preparation, food shopping, safe food handling, and basic nutrition. In rural areas, the EFNEP paraprofessionals who teach the lessons make regular home visits for 6 months to a year if a homemaker is unable to join an EFNEP group in their area. This personalized instruction allows paraprofessionals to adapt their teaching to the circumstances of individual households and, in the process, gain the trust and confidence of women whose behaviors often place them at

risk for chronic disease. For these women, economic and social circumstances may prevent them and members of their immediate and extended families from receiving regular medical care or participating in screening activities. In each of the NALIC states, EFNEP staff and paraprofessionals will be invited to participate in the program.

In Maryland, New York, and Pennsylvania, CES promotes health and nutrition education as well as community leadership education through many publications that are provided free or at a minimal charge to state residents. Within the counties, numerous extension programs address health or nutrition topics, community issues, leadership development, and working with at-risk audiences. Fifteen of Pennsylvania's cooperative extension workplans for the 1992-1995 period address health issues; 12 workplans concern leadership development and issues involving youth at risk.

CES has a long history of developing the leadership skills of both youth and adults who live in rural communities and of encouraging leaders to use their skills to improve the quality of life in rural areas. To this end, CES in the NALIC area participates in the National Family Community Leadership Program, in which extension volunteers at the local level learn how they can work with others to make a difference in their communities. Currently, trained program volunteers live in nearly half of the Appalachian counties in the NALIC region.

In addition, CES at Penn State, Cornell University, and the University of Maryland works closely with a number of university-based institutes and organizations that are directly involved with rural health. For example, at Cornell, the Community and Rural Development Institute supports 18 health and nutrition programs, whereas at Penn State the Northeast Regional Center for Rural Development has a continuing interest in health issues affecting rural communities. Pennsylvania's State Office of Rural Health, housed at Penn State, has as its ultimate goal to improve rural residents' access to quality health care, including hospitals, physicians, and mental health care and other services.

The NALIC project will link the American Cancer Society and Cooperative Extension Service to tap the cooperative spirit that is characteristic not only of individuals but also of organizations in the rural Appalachian counties of Maryland, New York, and Pennsylvania. The project will attempt to answer the following questions about this process:

- Can CES and ACS work together and with rural communities that have limited resources to carry out cancer prevention and control activities?
- Can CES and ACS form and support sustainable local cancer prevention and control coalitions?
- What is the membership (grassroots participants, professionals, lay leaders) of the coalitions formed and supported by CES and ACS?
- What are the differences between the coalitions and their activities in counties where participation by hard-to-reach rural residents in screening and educational programs is higher and in counties where participation is lower?
- What demographic and organizational features characterize counties where CES and ACS staff joined NALIC early in the project, compared with those who became involved at a later date or who chose not to participate?

During the planning phase, NALIC also is discussing the possibility that communities might be encouraged to:

- Provide cancer education or screening activities at worksites;
- Involve schools in cancer education activities through the inclusion of cancer information in school curricula;
- Develop partnerships with the media to deliver cancer education messages to the public;

▶ Use cancer education materials appropriate to the literacy level of targeted audiences; and

▶ Utilize a participatory process for developing cancer education plans and programs.

The NALIC evaluation plan will assess the extent to which coalitions are involved in these activities.

Building a Network of Coalitions

The project organizational structure of NALIC depicted in Figure 1 includes three field coordinators working in subregions that may encompass counties in more than one state. These field coordinators will support the ACS/CES team of professional staff and volunteers in planning and implementing local cancer control activities.

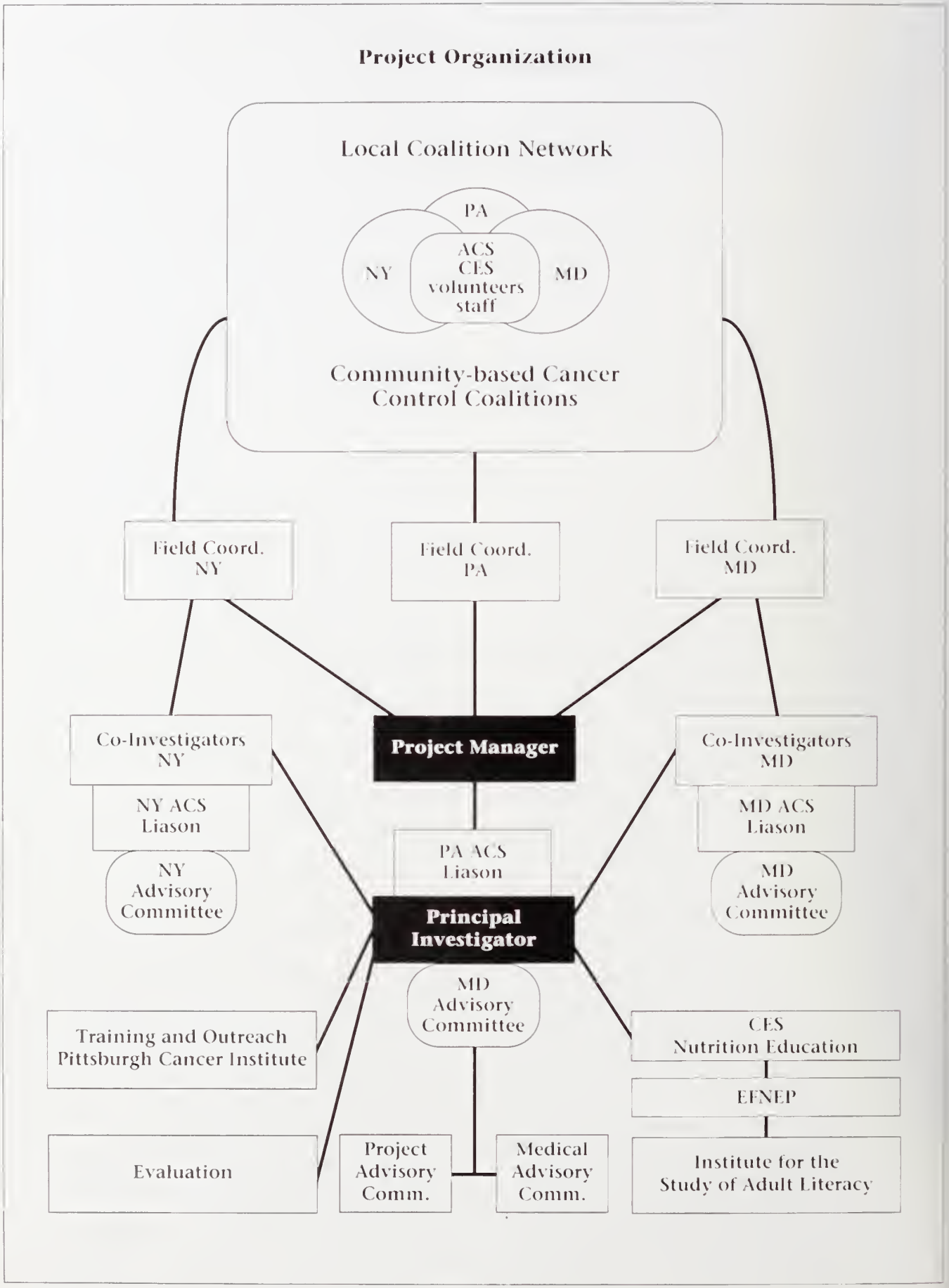
During the first months of the project, field coordinators will help initiating committees clarify the coalition's goal, conduct needs assessments, identify available cancer control resources, and initiate coalition-building activities. Field coordinators also will provide coalitions with relevant cancer data from state health data centers and information on statewide cancer prevention and control resources for use in targeting cancer control activities. They will provide each coalition with a local leader's handbook that will provide information on needs assessment, coalition formation, resource identification, evaluation, activity planning, and other issues that may arise during planning and implementation. The field coordinators will initiate skills development workshops when they are needed, designed by NALIC staff to inform coalition members about community health, coalition building, cancer prevention and control, rural Appalachia culture, and problems encountered by low-income, medically underserved populations. Additional educational activities will be conducted on how to assess local needs, organize communities around cancer issues, write grants, manage intergroup conflicts, set goals, establish networks, and work with the local media.

The Pittsburgh Cancer Institute will be responsible for the training and outreach components of NALIC, including seminars on specific cancer prevention and control issues for CES/ACS teams. They will develop a special NALIC cancer education program handbook containing an annotated bibliography of education resources to assist the local coalitions in identifying program materials. Particular attention will be paid to the inclusion of materials for low-literacy audiences.

Established coalitions will become a support and communication network not only for each other but also for newly forming coalitions. Regular communication among coalitions will occur through traditional CES and ACS channels, including a statewide computer network (Penn State's PSU*PEN system) that will allow most ACS/CES teams to communicate inexpensively with field coordinators and with each other. Other strategies to promote information exchange include regular meetings of coalition members from counties within the three NALIC subregions to share ideas, problems, and successes. A quarterly newsletter will update communities on the work of the coalitions. The newsletter will include a question-and-answer column that will address barriers to efficient community cancer prevention and control as well as specific issues of concern to cancer survivors and their families. At the project level, the NALIC project staff will meet frequently both in person and electronically to address issues of program implementation and management as they arise.

After compiling a list of potential members of a project advisory committee, NALIC's executive committee recognized the logistical difficulties of assembling members for a committee from a large, three-state area as well as the need to acknowledge the specific circumstances and concerns of each multicounty region. Consequently, project staff members decided that, in addition to a projectwide advisory committee, each of the three subre-

Figure 1. NALIC project organization



gions would have its own regional advisory committee. Several representatives from each regional advisory committee will participate in project advisory committee meetings. The project advisory committee will focus mostly on strategic planning issues and organizational sustainability, whereas the regional advisory committee will be concerned with project implementation and local sustainability. One important function of the regional advisory committees will be to exploit the connections within and between local cancer coalitions, which include county or regional education and health and human service agencies, and the project advisory committee, which has alliances with the regional and state departments of these agencies. In their efforts to sustain a comprehensive cancer prevention and control network throughout the region, the NALIC staff and the project advisory committee will build on the basic interorganizational coalition between ACS and CES to create community coalitions that in time can stimulate the formation of interagency coalitions in each of the states.

NALIC staff members have established a medical advisory committee to help the project and field staff involve the medical community. The role of this committee is to link coalitions with the medical community in the most effective way and to provide a neutral perspective on economic issues, such as local competition among health care providers. The medical advisory committee can help legitimize coalitions as they establish themselves in the health care mosaic of the communities. The committee also will review cancer education materials for accuracy and proposed programs for feasibility. The medical advisory committee includes doctors, nurses, and social workers who have experience working on cancer at the community level. Members of the medical advisory committee have been recruited through ACS divisions, the PCI network, and the Central Pennsylvania Oncology Group, which conducts clinical trials and cancer prevention and control programs in central Pennsylvania.

Developing and Disseminating Intervention Programs and Strategies

The field coordinators and ACS and PCI staff will provide coalitions with a descriptive list of various cancer prevention and control activities that have been employed with relative success in other settings. Coalitions then will consider the unique needs of their own communities, the resources needed to implement the activities described, the resources available in their communities, and the consequences for their community of choosing a particular activity. This information will help coalitions select the most feasible type of activity to initiate locally at a given time.

The effective use of this list of program descriptions assumes the existence of a relatively sophisticated community-based health coalition that is able to consider alternative approaches to cancer prevention and control in the community. To develop this level of competence, the coalition's initiating committee will conduct a cancer prevention and control needs assessment on which coalition members can draw to assess available resources, including health facilities, health professionals, and specialized services that are currently serving the area. Findings from the needs assessments will help the coalitions set community-specific goals for their cancer prevention and control activities.

The primary rationale for teaching coalitions to assess alternative cancer prevention and control activities is the empowerment of communities to enable them to identify their own needs, generate resources within the community, and access previously untapped resources from outside the communities. Although the staff members of NALIC assume that early progress will depend on the help of the ACS/CES teams and the field coordinators, they expect local coalitions and the

communities they represent to become self-directed in cancer prevention and control planning over the 5 years of the project. The project staff members hope to achieve this self-sufficiency by placing the responsibility for leadership development and program decision-making within the community itself. In addition, a coalition's initial success in identifying and securing needed cancer prevention and control resources, carrying out creative and stimulating cancer prevention and control projects, and communicating back to the community the outcome of efforts to reduce cancer risks is expected to build the local image of the coalition as an effective force in the community.

Project Evaluation

With the assistance of the ACS/CES team, NALIC staff routinely will collect data to evaluate the effectiveness of the project and demonstrate to communities the extent of the cancer problem in their area. NALIC evaluation staff will obtain cancer registry data and Behavior Risk Factor Surveillance System data from state health departments annually. The project evaluation team will design a tool to collect data on the availability and use of local cancer education and screening programs. By including representatives of state cancer prevention and control offices on its project and regional advisory committees, NALIC will be able to ensure consistency between the design of this data collection tool and the goals of state cancer prevention and control plans.

NALIC evaluation staff members also are analyzing information on the availability of health services within the region, which was gathered by the Appalachian Regional Commission. By mapping the use of cancer prevention and control services that are available to program activities in the region, the project hopes to stimulate the development of pertinent research questions regarding these services and their utilization. In addition, NALIC will use data on socioeconomically disadvantaged populations, which are being compiled by ACS. ACS also will play an important role in the collection of information on indicators of knowledge about prevention and early detection of cancer, tobacco use rates, and the numbers and types of people who contact ACS as a result of NALIC project efforts.

NALIC staff members are considering involving CES 4-H program members in some of the assessment procedures and coalition efforts. For example, the project may consider implementing a high school education program to focus specifically on peer-group tobacco education. In such a program, 4-H youth might survey their peers about tobacco use and participate in an antismoking campaign. Youth also may be asked to assist with a communitywide survey to determine knowledge of cancer prevention behaviors.

NALIC staff members are inviting faculty members and students from the Pennsylvania State University, the University of Pittsburgh, Cornell University, the University of Maryland, and other institutions of higher education in the region who are interested in cancer issues to conduct studies in cooperation with the project. These individuals may be willing to perform functions such as conducting assessments, testing education program models, and developing spinoff proposals. NALIC's rationale for involving interested academicians and ACS and CES volunteers in the project is to enhance sustainability and promote institutionalization of the project's goals.

Process Evaluation

NALIC staff will evaluate the implementation process using the "4-Cs" model for describing the level of involvement of individuals and organizations in the community coalition (Astroth 1991). This model illustrates community coalition building as occurring in four phases:

► Communication, where individuals establish communication links to exchange information and resources;

► Cooperation, where individuals work together informally to accomplish a specific goal;

► Coalition, where organizations participate in a more formal way around an issue or a common set of interrelated issues; and

► Collaboration, where organizational relationships are formalized with long-term commitments to address issues of mutual concern.

Community cancer coalitions may be functioning at all four levels simultaneously, but usually the goal is to progress from communication and cooperation to coalition and, ultimately, collaboration. Therefore, NALIC's process evaluation will gather data on all four types of activities.

NALIC will obtain both qualitative and quantitative process evaluation data concerning every coalition and coalition-generated program that is part of the project. Outcome data regarding the number of persons participating in coalition-sponsored programs as well as data on program participants' demographic characteristics will be used to describe the participants and how they, as a group, compare with the population of the county as a whole. NALIC will collect the following kinds of process information:

► Structure and membership of community cancer coalition committees;

► Interaction patterns among members;

► Issues and situations resulting in conflict, cooperation, and collaboration;

► Leadership patterns, including how coalitions and CES/ACS staffs function;

► Contacts between the coalition and local health care providers;

► Programs undertaken to inform and involve other community groups;

► Efforts to establish and maintain communication between lay persons and professionals in the community; and

► Program costs.

Staff members who collect this information will be asked to provide detailed descriptions of project activities and to track programs over time. This formative research will be an ongoing process throughout the program and will be the basis for continuous program improvement.

NALIC coalition members will play a role in many phases of the assessment and evaluation process. The CES/ACS team will use general guidelines or "goalposts" for building coalitions, assembling data to help identify community needs, promoting cohesive group relationships, and conducting effective cancer prevention and control activities. Through these self-assessment activities, NALIC staff members hope to promote a greater sense of ownership and responsibility for cancer prevention and control decision making within the coalition and the communities. Project staff members will share outcome data with the coalitions to help in the continual assessment of their work.

Outcome Evaluation

Outcome measures for NALIC incorporate those specified in *Healthy People 2000* (U.S. Department of Health and Human Services 1991), including reductions in the percentage of Appalachian residents who use tobacco products; increases in the proportion of Appalachian women who receive clinical breast examinations, mammograms, and Pap tests; and increases in the proportion of Appalachian residents who visit primary care providers and receive oral, skin, and digital rectal examinations. Because this project is attempting to build the capacity of communities to create their own cancer plan, additional criteria for evaluation of NALIC coalitions will be based on those contained in *Healthy*

Communities 2000 Model Standard: Guidelines for Community Attainment of the Year 2000 National Health Objectives (American Public Health Association 1991). These criteria refer to the community's ability to define its own objectives.

NALIC will use three types of outcome measures to evaluate the impact of the project.

► Data from the Maryland, New York, and Pennsylvania cancer registries concerning the number of persons diagnosed by cancer type, stage at diagnosis, age, and sex will be aggregated by county, allowing NALIC to relate the data to the type and frequency of cancer education and screening programs in each county. Stage at diagnosis is the principal dependent variable of interest. If the cancer outreach efforts of this program are successful, there should be an increase in the percent of persons diagnosed at earlier stages of disease.

► Data from the Behavioral Risk Factor Surveillance System for Maryland, New York, and Pennsylvania will be used to describe cancer-related behavior patterns characteristic of the entire NALIC region and the three subregions on factors such as smoking cessation, breast self-examination, and other risk reduction behaviors.

► The number of persons participating in cancer education, screening, diagnostic, and therapeutic cancer activities will be determined by NALIC staff. Historical baseline data will be obtained from agencies, hospitals, and the Maryland, New York, and Pennsylvania divisions of ACS. NALIC evaluation staff will compare these baseline data with data collected after the implementation of cancer prevention and control programs. Association between the degree of change and the degree of community cancer initiative activity can suggest characteristics of project effectiveness.

Outcome data also will have important implications for the process evaluations. For example, data comparing the characteristics of counties with different participation rates can help identify the critical features of effective coalitions. This information then can be used to help increase participation in low-activity areas.

Cancer registry and behavioral risk data also can be used for programmatic purposes. Selected registry data for each county will be given to the community coalitions to demonstrate the extent of the cancer problem in their communities. Behavioral risk data for the entire NALIC region and the three subregions will be used to demonstrate the need for changes in health behaviors among residents.

NALIC staff members recognize a number of important limitations to interpreting program outcomes from these data. For example, other factors in addition to this program will affect participation in screening programs. Nevertheless, trends are likely to be useful in generating hypotheses to be tested in further studies. Another important limitation of using cancer registry data is the traditional 2-year lapse between the dates when data are submitted and when they are processed and ready for analysis. Consequently, this analysis cannot be done before the third project year; in year 5, data will be available through the third project year only.

Initial Planning Issues

NALIC is addressing a number of issues during its planning stage. The restructuring of the project's advisory committee into three regional advisory committees in addition to the overall project advisory committee was a response to concerns about addressing important regional differences within the NALIC project area as well as promoting project integrity and collaboration throughout the large geographic area served by NALIC. Crucial issues include promoting communication between distant members of the project staff, coordinating linkages between CES and ACS counterparts, and making connections with other state and federal organizations

concerned with rural and health issues. Timely and consistent communication between CES and ACS also is limited by restrictions on resources, which include funds and time as well as personnel. These limitations affect other aspects of the project. For example, NALIC recognizes that the measurement of behavior change and the process of coalition building require a detailed evaluation methodology. However, funding and staffing restraints limit the scope of the evaluation plan.

The NALIC staff believes that small incentive grants would be highly desirable to encourage new coalitions to begin project activities. Finding ways to acquire, manage, and disseminate these funds is an important issue during NALIC's planning stage. NALIC also is concerned about the implications of promoting cancer screening for rural and low-income individuals, many of whom may lack health insurance, without being able to provide followup care and treatment for cancers that are detected. Ideally, the community should develop a plan to provide for this eventuality. However, the community may not be able to confront this issue immediately.

NALIC staff members share, with staff from many similar endeavors, the challenge of creating a shared vision of the project among participants with diverse backgrounds and personal experiences. Project members with a medical orientation view the project's mission differently than do members with a more grassroots orientation. Project staff members are not equally convinced of the value of community-based coalitions, particularly those that include people who have limited incomes and reside in rural areas. Some CES and ACS staff members who are participating in NALIC view the project's objectives from a perspective focused on programs and activities rather than coalition building. These individuals perceive the need for concrete and immediate program activities and would prefer to implement cancer programs before building coalitions. Because both CES and ACS are oriented organizationally to demonstrating program impact, many of their staff members prefer to focus on short-term, readily measured, educational and behavioral outcomes. Coalition building does not lend itself to this model. It requires a significant investment of time, does not yield measurable impacts in the short term, and places staff in highly unstructured situations. These factors may deter busy professionals from making a commitment to NALIC involvement. Assuring participants of the long-term benefits of coalitions is an important goal during the implementation of the project.

Many CES and ACS staff members involved in NALIC are concerned about the appropriate geographic limits of a community coalition. Staff members from both organizations are county focused. Nevertheless, the project may need to involve an area that is larger or smaller than a county. Therefore, the concept of community will not be consistent from coalition to coalition. In some areas, counties may be divided geographically. In other areas, county boundaries may be overlooked by local residents. By prompting coalitions to define their own geographic boundaries, NALIC hopes to draw on the natural linkages and networks that traditionally exist in the rural areas.

NALIC project staff also must consider the extent to which the project should address local environmental issues such as toxic waste sites, incinerator projects, and industrial effluent. Although controversy surrounding these issues reflects concern about potential carcinogenicity, focusing on the issues may distract people from considering those cancers in which the outcome can be affected more readily by education and outreach programs that target prevention and screening practices. NALIC staff members are aware that they may need to investigate additional resources for coalitions that choose to confront environmental concerns.

Project Characteristics of the Northern Appalachia Leadership Initiative on Cancer

1. The Northern Appalachia Leadership Initiative on Cancer (NALIC) will be implemented by the Cooperative Extension Service (CES) at Pennsylvania State University in association with the CESs of the University of Maryland and Cornell University. Divisions of the American Cancer Society (ACS) in Maryland, New York, and Pennsylvania and the University of Pittsburgh also will participate in NALIC.

2. NALIC will serve an area of rural communities with people of various ethnic origins.

3. Through state ACS divisions, NALIC will extend and adapt current activities of the extension services in Maryland, New York, and Pennsylvania.

4. NALIC will involve a broad spectrum of community members recruited from senior citizen centers, high school

continued

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clubs, fraternal and service organizations, volunteer fire departments, craft clubs, church groups, and sports teams.

5. Initiating committees will conduct needs assessments of their respective communities to identify cancer concerns of the community, the county-specific levels of cancer incidence and mortality, the resources available in the community to provide a cancer training and outreach program, the history of cancer outreach activities in the community, and the areas of greatest social and economic need in the area.

6. NALIC will evaluate the extent to which coalitions are involved in the following: providing cancer education or screening activities at worksites and in schools, developing partnerships with the media to deliver cancer education messages to the public, devising cancer education materials appropriate to the literacy level of target audiences, and using a participatory process for developing cancer education plans and programs.

7. NALIC will develop a support and communication network of established and newly formed coalitions and will foster communication through a statewide computer network, quarterly newsletters, and regular meetings of coalition members.

8. NALIC will form regional advisory committees in addition to a project advisory committee made up of representatives from the regional committees. The project advisory committee will focus on strategic planning issues and organizational sustainability; the regional advisory committee will focus on project implementation and local sustainability.

9. NALIC will use a medical advisory committee made up of doctors, nurses, and social workers to help link coalitions with the medical community and to review cancer education materials for accuracy and programs for their feasibility.

10. NALIC will assist coalitions to assess alternative cancer prevention and control activities as a means of empowering communities and enabling them to identify their own needs, generate resources within the community, and access untapped resources from outside the communities.

11. NALIC will collect data routinely to evaluate the effectiveness of the project and assess the extent of the cancer problem in a community. NALIC evaluation staff will analyze information on the availability of health services within the region, as well as indicators of knowledge about prevention and early detection of cancer, tobacco use rates, and the number and types of people who contact the ACS in response to NALIC's efforts.

The project staff members of NALIC recognize that coalition building may not be the only avenue to achieve effective cancer prevention and control in a rural Appalachian community. Coalition members may need to consider ways to build communication and cooperation within these communities to promote programs that will attract rural people who are not traditionally reached by medical services.

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CHAPTER 12

North Central Appalachia Leadership Initiative on Cancer

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Institutional Context

The Mary Babb Randolph Cancer Center (MBRCC), part of the West Virginia University Health Sciences Center in Morgantown, West Virginia, will be responsible for directing the North Central Appalachia Leadership Initiative on Cancer (NCALIC) project in West Virginia and Ohio. This project will target all 84 Appalachian counties in the two states. MBRCC will collaborate with the Riverside Regional Cancer Institute at Riverside Methodist Hospital in Columbus, Ohio, to coordinate NCALIC activities in the Appalachian portion of southeastern Ohio.

MBRCC has a history of service related to the National Cancer Institute's (NCI) Appalachia Leadership Initiative on Cancer (ALIC) program goals. It currently provides integrated, cancer-related services to residents of West Virginia. Programs emphasize community-based approaches to cancer prevention and control, including education and outreach. MBRCC trains health professionals and educators to effectively reach their clients with information on early detection of breast and cervical cancers, smokeless tobacco and smoking cessation, and nutrition. Through its extensive work with the Cancer Information Service (CIS) of NCI, MBRCC has deepened its knowledge of cancer needs and cancer-related attitudes and risk behaviors of West Virginia's population.

MBRCC's partner, the Riverside Regional Cancer Institute, has 65 clinical and educational programs throughout Ohio, many of which are located in the southeastern counties. The complementary strengths of MBRCC and Riverside in cancer education and outreach and their prior work together create the basis for this partnership.

Populations to be Served

The North Central Appalachia Leadership Initiative on Cancer project serves Appalachian Ohio and all of West Virginia, a region with more than 68 percent of its counties classified as rural (see Figure 1 in the Introduction to Section III). According to U.S. 1990 census data, the median age of the counties' residents and the portion of residents age 65 and older have increased over the 1980s. The median age of residents of Ohio's 29 Appalachian counties increased by 3.8 years during that decade (from 30.4 years in 1980 to 34.2 years in 1990). In West Virginia, the median age increased by 5 years (from 30.4 years in 1980 to 35.4 in 1990). Between 1980 and 1990, the group age 65 and older increased by 1.8 percent in Appalachian Ohio counties and 2.8 percent in West Virginia (U.S. Department of Commerce 1991). The primary reason for the increase in the proportion of older people is a decrease in the younger population.

According to the 1990 census, low literacy is a particular problem in the NCALIC region for persons age 25 and older. In the 29 Appalachian counties of Ohio, 32.8 percent

of the adult population have not graduated from high school, and 13.1 percent have less than a ninth-grade education. Thirty-seven percent of adult West Virginians have not graduated from high school, and 20 percent have less than a ninth-grade education (U.S. Department of Commerce 1991).

The percentage of individuals with limited literacy skills is higher in the more isolated counties. For example, in West Virginia, 58 percent of McDowell County residents age 25 and older have not graduated from high school. Thirty-two percent of this same age group have less than a ninth-grade education. In Holmes County, Ohio, 53 percent of residents age 25 and older have not graduated from high school, and 33 percent have less than a ninth-grade education (U.S. Department of Commerce 1991).

West Virginia's first immigrants settled there in the early 1700s. The Germans and the Scotch-Irish came to escape religious sanctions in their home countries (Bice 1979). People from Holland, Ireland, Scotland, England, Wales, and Sweden arrived with the hope of owning land. These settlers helped build the state's earliest industries, which included lumber, grain, farming, gunpowder, salt processing, and boat making. The rugged terrain of West Virginia consists of mostly hilly plateaus and forested mountains; therefore, most of the industries and towns were located along rivers (Bailey 1965).

Access to the state's interior and to surrounding states improved with the arrival of railroads during the latter third of the 19th century. Constructed to serve West Virginia's coal industry, railroads penetrated into nearly every part of the coal region. Because local workers were scarce, laborers relocated to West Virginia to work on the railroads. Existing towns grew, and new towns were established. The completion of the railroads signaled the birth of the coal industry (Rice 1972). By the end of the coal era, outside corporations owned most land and mineral rights

in West Virginia. Thus, this "progress" left West Virginians feeling isolated and hostile.

Floods of European immigrants, especially those from Poland, Hungary, and Italy, came to West Virginia to work in the mines (Sutton 1968). Because mine locations were frequently isolated, the coal companies often built towns for their workers that included company-owned homes, stores, and churches.

The United Mine Workers of America was formed in 1890, and by 1902 most coal mines in the state had unionized. The advent of railroads and the coal industry encouraged the growth of many other industries. Metal, glass, chemical, and textile industries developed to utilize West Virginia's other natural resources, including salt, natural gas, oil, limestone, clay, sand, gravel, and timber. These extractive industries brought great prosperity during boom times but left scarred lands, poverty, and towns without hope (Bice 1979). This history of prosperity and hardship helped to shape the mountaineers' heritage of self-reliance, independence, and hard work. The West Virginia motto, "Montani Semper Liberi" ("mountaineers are always free"), exemplifies this heritage.

The history of Ohio's Appalachian region dates back to 800 B.C. and the ancient Indians. As part of one of the continent's strategic crossroads, this area attracted people from a variety of regions and countries, resulting in a rich cultural heritage and significant diversity (Durrance and Shamblein 1976).

Appalachian Ohio is an area of steep-sided hills and valleys referred to as the Appalachian Plateaus. It extends from the Ohio River valley into the wooded foothills west of the Allegheny Mountains. Because of the state's central location and the Appalachian region's location on the Ohio River—the "River to the West" for waves of immigrants—Ohio attracted settlers from all parts of the country (Durrance and Shamblein 1976). As greater amounts of land opened up for settlement in the late 1700s and early 1800s, immigrants from England, France, Germany, Ireland, and Scotland moved to Ohio. At that time, agriculture was the state's major industry. Germans who were escaping economic and political problems in Europe settled in or near the larger cities in Appalachian Ohio. Ohio's antislavery stance and alignment with the Union during the Civil War stimulated migration of African Americans from the South (*Encyclopedia Americana* 1979).

Ohio's central location and its accessibility to natural resources, power, transportation, and markets shaped the evolution of industry. Advances in the coal and steel industries brought a second wave of immigrants to Appalachian Ohio. Other regional industries involving chemicals, metal production, stone, clay and glass products, machinery, and pulp and paper products became increasingly productive at the same time. This industrial development drew large numbers of immigrants from Italy, Czechoslovakia, Poland, Hungary, Greece, Yugoslavia, Russia, and other southern and eastern European countries to the region.

A third wave of migration to Ohio occurred during and after World War II when residents of West Virginia and Kentucky moved to this region in search of employment. An additional number of African-Americans also relocated at this time to the region's metropolitan areas (*Encyclopedia Americana* 1979).

Common Characteristics of NCALIC Communities

NCALIC views "community" as an entity composed of individuals who interact with each other in one section of a large county, within the entire county, within several counties, or in contiguous counties across state lines. One typical community that NCALIC will target exists at the fork of three 3,000-foot mountains, 90 minutes from an interstate highway in central West Virginia. Although only 2,100 people live in town, this county seat serves a population of 10,729. It can be

reached by three divided two-lane highways that descend at brake-burning angles down a mountain with a 200-foot drop on one shoulder. During winter storms, the roads are impassable; during heavy rains, the roads wash out; on a fair day, the roads seem to lead to Eden.

According to the 1990 census (U.S. Department of Commerce 1991), nearly as many men live in this county as women. Almost 16 percent of county residents are age 65 years or older, a 2.5-percent increase from 1980. Thirty-five percent of the families in this county live below the federal poverty level. Fifty-three percent of those age 25 and older have not graduated from high school; of those who have not graduated, 34 percent are not educated beyond the eighth grade.

The people in this community who do not own a truck or car can rely on the Mountain Transit Authority bus, which travels to the next town (irregularly) three times a week. However, commuters must find a way to get to town to catch the bus. An alternative means of transportation is the town's one taxi parked in front of the Dollar Store. A senior center van will pick up anyone along the main roads who can afford to come to town on Tuesday for a potluck lunch. Most rural residents rely on each other for transportation as they do for companionship, help in coping with misfortunes and emergencies, and health information.

Business owners, school teachers, the town surgeon, the general practitioner, the dentist, and six lawyers are among the "affluent" members of the community who live in town. Branching off each main road are dirt roads that lead to "hollers" that wind along rivers and the mountain ridges. Other people live in "company towns" long ago deserted by the coal industry. The poorest people live along the river "below town"; until 1979, raw sewage was dumped routinely into the river.

Like most residents of West Virginia and Appalachian Ohio, people in this typical rural community live no more than 30 minutes from their place of birth. The "hollers" are populated with families, branches of families, and people who attend the same local church. These people do not identify with those who live in town. They come to town only on Saturdays, when they buy supplies and chat with each other on the courthouse lawn. Other gatherings may focus on church, bluegrass music, reunions, and funerals.

These rural residents believe they are healthy if they can continue to do necessary physical work. Only when they can no longer work in their gardens, haul wood, or tend their animals do they believe that they have health problems. Their concept of preventive medicine usually does not extend beyond advice from family and traditional folk remedies. If these residents have a television, they may try advertised over-the-counter medicines. A source of primary care may include irregular visits to the one nurse who works for the county health department. Problems concerning domestic disputes, children in school, aging, and chronic disease are addressed by the Seneca Mental Health Center. The local hospital serves members of this community in the emergency room but offers no preventive services.

This typical community demonstrates the need for NCALIC to overcome barriers that include illiteracy, distrust of outsiders, distrust of medical language, and lack of transportation. However, NCALIC communities have developed informal mechanisms for working together on common problems. Within the most rural areas served by NCALIC, people meet at church, after church services, or at potluck socials to discuss group and individual problems. For example, they may consider ways to collect firewood during the winter for a neighbor who has had a stroke. At the "town" level of community, people hold informal meetings. Community leaders communicate by word of mouth, announcements at the end of church services, notices in the

local newspaper, or announcements by the local disk jockey. For example, local leaders may announce that everyone is invited to gather at the high school gymnasium to talk about raising money for the town library. Solutions emphasize cooperation, raffles, potluck dinners, and bake sale proceeds.

NCALIC has the opportunity to work with and build on this tradition of community cooperation and mutual support to address the problem of cancer in rural Appalachia.

Incidence and Risk of Cancer

NCALIC is working in a region where rates of cancer mortality are notably higher than national rates. According to *Cancer Statistics Review 1973-1989* (Miller et al. 1992), mortality rates are particularly high in West Virginia for lung and cervical cancers and in Ohio for breast, colon, and rectal cancers. West Virginia ranked third nationally in the 1985-1989 average annual age-adjusted mortality rate for lung cancer and fifth for cervical cancer. Likewise, Ohio (only a portion of which is in Appalachia) ranked 11th nationally for overall cancer mortality, 9th for breast cancer, and 11th for colon and rectal cancers. The incidence of certain cancers, such as breast and colon cancers, in West Virginia and southeastern Ohio also may be increasing at a faster rate than the incidence for the United States.

The north central portion of Appalachia is largely medically underserved and is characterized by poor compliance with early detection guidelines and cancer prevention behaviors, including higher rates of tobacco use than in the nation as a whole. For example, West Virginia leads the nation in smokeless tobacco use and overall tobacco use. Many Appalachian residents are still unaware of where or when to seek early cancer detection, how to proceed when they are diagnosed with cancer, or how to navigate through an increasingly complex and technical health care system.

Mobilizing Leaders

A key strategy for mobilizing local leaders involves familiarizing the community with cancer problems and how the NCALIC plans to address these problems in a particular area. NCALIC is initiating its mobilization efforts with a series of educational training meetings, to be conducted through the Mary Babb Randolph Cancer Center in Morgantown. The purpose of these meetings is to identify agencies and individuals who will form a matrix coalition involving state, regional, and local intermediaries.

MBRCC and the Riverside Regional Cancer Institute in Columbus, Ohio, have initiated a series of planning meetings with NCALIC's key collaborators—county and state health departments and American Cancer Society (ACS) divisions in West Virginia and Ohio. These agencies will assist NCALIC in identifying other intermediaries at all levels. A series of presentations by NCALIC staff will lead to the identification and recruitment of state and regional intermediaries and, through these contacts, of community leaders who will serve as coalition coordinators.

MBRCC and the Riverside Regional Cancer Institute sent letters introducing NCALIC and its goals and objectives to potential state intermediaries. The letters were followed by scheduled presentations that introduced NCALIC and outlined areas of potential long-term collaboration. At these meetings, NCALIC staff members discussed cancer problems and issues specific to the state and region, defined "rurality" to help identify target regions or counties, and discussed NCI's cancer priorities and target populations of special concern.

Individuals and agencies recruited at these meetings will help enlist intermediaries to work with NCALIC staff at the regional level. Potential regional intermediaries include representatives of the Wellness Coalition and the Health Promotion Network; members of the State Health Education Council; patient edu-

cators from clinics and hospitals; and regional coordinators for the Breast and Cervical Cancer Screening Program of the Centers for Disease Control and Prevention (CDC), NCI's American Stop Smoking Intervention Study for Cancer Prevention (ASSIST), and Rural Cancer Intervention.

NCALIC presentations to potential regional intermediaries include material presented at the state level as well as region-specific data on cancer mortality and demographics. Project staff will solicit the audience's perspectives on cancer problems and issues in the various regions as well as suggestions regarding regional resources that may be available to NCALIC. These regional meetings also will serve to identify ongoing cancer-related activities, thereby avoiding duplication of effort. Possible areas of collaboration such as industries and worksites will be explored.

Regional intermediaries will be asked to suggest active leaders and decision makers at the community level who may wish to head an NCALIC coalition. Potential community leaders include private rural practitioners, nurse practitioners, physician assistants, school principals, librarians, county extension agents, ACS leaders, business and industry leaders, church and civic leaders, homemakers, senior citizens, local elected officials, emergency service personnel, and media representatives.

NCALIC regional contacts will invite potential coalition members to a town meeting, where community leaders will be introduced to NCALIC project staff and the coalition concept. In addition to presenting information included in the regional orientation meetings, project staff members will discuss the logistics of coalitions and their central role in NCALIC. Local leaders will be invited to join NCALIC efforts in building community-based cancer prevention and control coalitions.

NCALIC's efforts to establish cancer prevention and control coalitions in West Virginia and Appalachian Ohio are designed to answer key research questions and achieve corresponding goals. The central research questions and goals for NCALIC are as follows:

► Can communities in West Virginia and Appalachian Ohio implement their own cancer prevention and control interventions? NCALIC plans to select potential coalition communities carefully; offer resources and technical support appropriate to their cancer-related concerns; build relationships at the state, regional, and local levels that will nurture these coalitions; and document the process by which communities unite and act.

► Can local coalitions implement cancer control interventions that will change the knowledge, attitudes, and behaviors of their communities? Through careful evaluation, NCALIC will be able to assess changes that can be attributed to cancer coalition activities.

► Can behavioral changes be sustained beyond ALIC? Through their involvement with NCALIC coalitions, communities may change the way they view health; individuals may learn that they have more control over their health; patients and health professionals may change their expectations about the services they receive or provide; and legislators may be encouraged to pass laws that improve access to cancer-related services.

Building Blocks of Coalitions

NCALIC will choose communities for cancer prevention and control coalitions based on rurality, availability of resources, demonstrated need for active cancer prevention and control interventions, and desire to sponsor coalitions. NCALIC will choose coalition members who represent the community and have access to all residents, especially minority and medically underserved populations. The cancer prevention and control coalitions will be comprehensive in breadth to target multiple systems such as schools, worksites, medical facilities, and civic organizations.

Each coalition will implement a unique and independent intervention, but the process for designing, implementing, and evaluat-

ing these interventions will be consistent. As coalitions begin to define their intervention programs, subcommittees will be formed to meet monthly to plan and execute various program components. These subcommittees may focus on topics such as materials development and review, media coordination, fundraising, public education, or efforts to reach special populations within the community.

NCALIC will offer local coalitions a wide range of technical assistance on topics such as planning programs, working with the media, evaluating progress, and writing grants. Coalition members need to feel that they and their communities receive direct benefits from their involvement with NCALIC. Such benefits might include supplying community members with materials and resources, offering expertise in technical areas, awarding certificates for new skills, and recognizing individuals and groups through the local media or at special events.

NCALIC has identified intermediaries with direct access to the target population. Several existing programs extend into communities and could become collaborators with NCALIC.

▶ Community Action Association, Inc., is an umbrella organization for member agencies that offer services to low-income people. Although the number and type of member agencies vary between states, most include Head Start and affiliates that provide surplus food distribution, home weatherization, job training, adult literacy and training programs, and rural transportation. Both Ohio and West Virginia have a Community Action Association with county or multicounty agencies. In West Virginia, for example, 19 separate local agencies collectively serve 50,000 low-income people. This organization can provide cancer information and education programs to elderly, low-income women who may be missed by other community programs.

▶ The Associations of Housing Authorities have access to thousands of Appalachians in each state who live in public housing. In West Virginia, for example, 38 separate local housing authorities serve more than 17,000 people. Many public housing facilities are staffed by resident services coordinators who, under the new resident initiative of the U.S. Department of Housing and Urban Development, can be credited with disseminating cancer information to their clients. The Associations of Housing Authorities and the Community Action Associations both are relatively untapped resources that can help reach the population NCALIC is targeting.

▶ Cooperative Extension Services, located in every county in the North Central Appalachian region, have extensive experience in developing and carrying out health education programs. The Family and Youth Development Extension Programs, for example, provide nutrition education during home visits to thousands of low-income audiences through the Expanded Food and Nutrition Education Program. MBRCC has trained extension homemakers to present community programs on smoking cessation, early detection of cervical cancer, and good nutrition. The Cooperative Extension Services will be a valuable resource to NCALIC coalitions.

▶ The YWCA's Women's Health Initiative includes the goals of assisting breast cancer survivors and helping women to overcome barriers to early detection of breast cancer. In mid-1993, YWCA will initiate a new program designed to help medically underserved and minority women to overcome the obstacles that prevent them from surviving breast cancer. This program, to be instituted in every YWCA, will include free breast health education workshops and screening services. Because they are targeting the audience NCALIC seeks to reach, YWCAs in West Virginia and southeastern Ohio will be valuable intermediaries in carrying out goals.

In addition, MBRCC is currently involved in two projects that will link with NCALIC.

► Breast and Cervical Cancer Screening in Older Low-Income Rural Women is a grant program funded by NCI. MBRCC is collaborating with a regional, multidisciplinary health department to demonstrate how a consortium of community agencies can develop and evaluate strategies to increase the availability, awareness, and utilization of breast and cervical cancer screening services. The target population is rural, low-income, unscreened women age 40 and older with an emphasis on women age 65 and older.

► The Linking Resources and Expanding Health Services in West Virginia: A Demonstration Project to Alter the Role of the Small Rural Hospital is a project funded by the W.K. Kellogg Foundation. This Kellogg grant, supplemented by the Benedum Foundation, covers a 15-county rural area of West Virginia. This project utilizes a network of "lay leaders," churches, extension agents, city councils, and so forth, to work with primary care clinics to reduce health-related problems of women and children. It addresses breast and cervical cancer screening, teaching risk factors for other cancers, nutrition and prenatal care, teenage pregnancy, and infant mortality.

MBRCC already is directing community-level programs for cancer information and screening. The Breast and Cervical Cancer Screening Program, funded by CDC, is increasing the number of women in West Virginia (and in Ohio as of 1993) who routinely receive mammograms and Pap tests and is providing continuing education programs for health professionals working with breast and cervical cancer screening. This program offers screening services at little or no cost to low-income women at or below 200 percent of the federal poverty level who are underinsured or uninsured. Persons are underinsured if their medical insurance does not cover screening services or if they cannot pay the required deductible or copayment. Women must be 40 years old to be screened for breast cancer under this program, and breast cancer screening promotions and materials target primarily women age 50 and older.

More than 100 county health departments and primary care clinics provide clinical breast examinations, teach women how to do breast self-examination, show NCI's *Once a Year for a Lifetime* video, and disseminate NCI and ACS materials on breast cancer. Eight registered nurses serve as cancer information specialists in West Virginia's public health districts. They work closely with MBRCC project staff to conduct the "You're Worth It" public education campaign in each of the counties they serve. Under this heading, MBRCC provides public service announcements (PSAs), low-literacy materials on breast and cervical cancers, special events and promotions, and educational talks; conducts volunteer training; works with local businesses to reach workers; and uses other strategies to reach women with program information.

CDC, NCALIC, and CIS project staff are conducting a survey of low-income women in randomly selected counties throughout West Virginia as part of the midpoint evaluation of the "You're Worth It" campaign and to provide baseline information for NCALIC. The survey will be replicated in Ohio by CDC and health department project staff and in the southeastern Ohio counties by NCALIC staff at Riverside in fall 1993. The survey will indicate to CDC project staff the extent to which "You're Worth It" materials have been effective in reaching the target population and any necessary changes. The survey will provide NCALIC staff with information on specific barriers and beliefs in very rural counties. This information is needed because CDC's Behavioral Risk Factor Surveillance System (BRFSS) and other surveys historically have used the telephone to collect data, which, as those who work in the rural counties realize, excludes much of the target population. Project staff members also are administering the Wide-Range Achievement Test to determine whether distributing easy-

to-read print materials is an appropriate strategy for reaching the target group. NCALIC staff will provide the results of the survey to NCALIC/CDC participants to help coalitions and businesses plan effective education and screening activities.

The Public Health Nurses Physical Assessment Training for Breast and Cervical Cancer Screening (PHNPAT) was funded by the Cancer Research Foundation of America in 1989 and endorsed by the West Virginia Bureau of Public Health. This program was designed to eliminate a variety of barriers to breast and cervical cancer screening. During three 5-day workshops, West Virginia University physicians and educators trained 43 public health nurses from 36 counties to recruit, screen, and educate low-income, underserved women in their communities who may never have had a Pap test or breast examination. The training package included a curriculum aimed at:

- Instructing and certifying nurses to perform Pap tests, pelvic exams, and breast examinations and to teach patients how to examine their own breasts;
- Teaching nurses (with press releases, radio PSAs, and low-literacy prevention materials provided by MBRCC) how to use the media and community networks to educate rural women and recruit them as patients; and
- Furnishing a Protocol for Cervical and Breast Cancer Screening endorsed by the West Virginia Bureau of Public Health to each clinic with a PHNPAT- trained nurse.

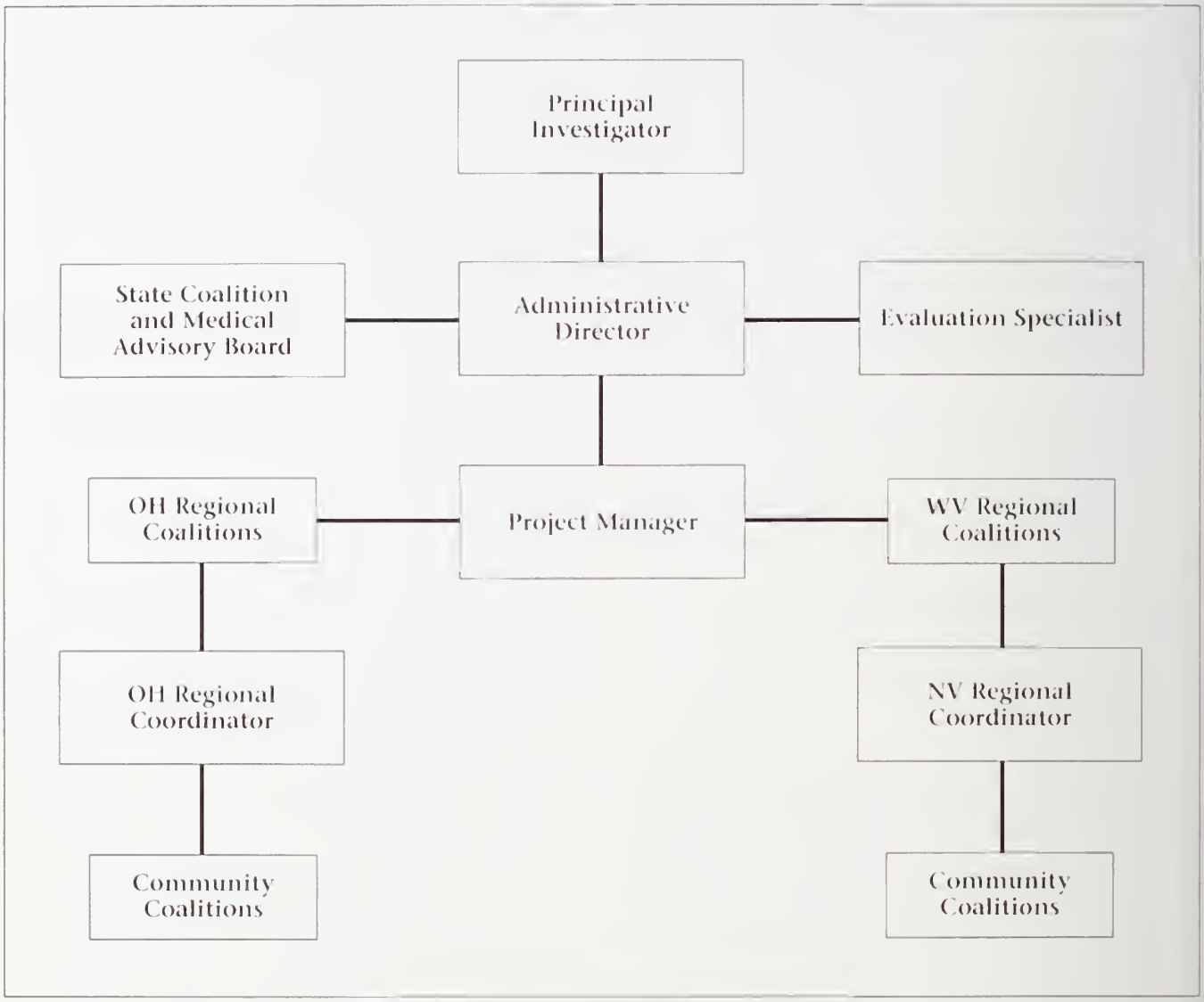
MBRCC currently runs the Cancer Information Service of Ohio, Virginia, and West Virginia, one of NCI's largest new regional CIS offices serving a population of 19 million people. As one of the 19 offices that serve the entire United States and Puerto Rico through its toll-free 1-800-4-CANCER telephone system, CIS provides cancer patients, their families, the general public, and health professionals with accurate, confidential answers to questions about cancer prevention, detection, state-of-the-art treatment, and community services. In 1992, more than 25 percent of CIS calls to this three-state area were about breast cancer detection, diagnosis, and treatment. CIS promotes facilities accredited by the American College of Radiology, CDC screening services, ALIC activities related to breast cancer, the National Black Leadership Initiative on Cancer, and special screenings offered through ACS and accredited cancer centers and community hospitals to interested callers. CIS also can provide feedback to projects and screening service providers on the number of calls received and callers who were referred.

The West Virginia CIS has produced a series of low-literacy fact sheets that NCI has approved for national distribution. Four of these fact sheets are on early detection of breast and cervical cancers. The West Virginia CIS also designed a training program for intermediaries on how to identify and work with low-literacy populations and how to develop materials for individuals with limited reading skills. These fact sheets and training programs will be offered to the NCALIC project staff members and coalition leaders.

Building a Network of Coalitions

NCALIC's project manager will supervise regional coordinators located at Riverside Regional Cancer Institute, which serves 29 southeastern Ohio counties, and at Mary Babb Randolph Cancer Center, which serves the 55 counties of West Virginia. Figure 1 provides NCALIC's organization chart. During the first year of its work, NCALIC will establish regional cancer control coalitions, which will develop local community coalitions. The project's network will include at least six regional coalitions in Appalachian Ohio and eight in West Virginia. Each regional coalition will have 18 to 25 members, who will meet at least quarterly. Potential coalition members will sign a letter of agreement that defines the responsibilities and benefits of coalition membership.

Figure 1. NCALIC project organizations



Regional coordinators will help coalition leaders develop their intervention programs by providing training on designing and implementing a cancer prevention and control program that will build community competence and confidence. Part of the regional coordinators' coalition training sessions will address reaching special populations and conducting community assessments to determine cancer education needs.

NCALIC will offer local coalitions cancer education programs that intermediaries can be trained to use. For example, training programs will address ways to reach low-literacy populations and develop appropriate materials for school-based smoking and smokeless tobacco cessation programs, cervical and breast cancer screening clinical procedures for nurses, nutrition education, and smoking and smokeless tobacco prevention for grades 2 through 8.

Rural Appalachian communities often resist academics and outsiders who come into the region and tell residents what to do. Consequently, with guidance from MBRCC and key intermediaries who are indigenous to the region, NCALIC is building a network of local coalitions that will choose programs and activities of interest to the communities. Regional coordinators will encourage local coalition members to assume the lead in the planning process.

To promote the exchange of information among coalitions, NCALIC will assign a coalition member to record all coalition activities as they are planned and implemented. This record will include reports from the subcommittees and minutes of the quarterly coalition meetings. It will be used to respond to requests from the media and will contribute to the development of the NCALIC newsletter.

Developing and Disseminating Intervention Programs and Strategies

NCALIC will offer coalitions a menu of pretested cancer education programs and materials that can be used and adapted for community projects. This menu will reflect NCI's priorities, which include cancers of the breast, cervix, lung, skin, colon, and rectum as well as issues associated with diet and smoking cessation. Members of the NCALIC project staff will present information about these priorities and associated screening guidelines during a slide presentation developed for the initial coalition meetings. NCI's Office of Cancer Communications will be the primary resource for cancer education materials. NCALIC also will use materials and programs developed by ACS as well as MBRCC's "training-the-trainer" programs and low-literacy materials approved by NCI. NCALIC project staff members will organize into a resource packet all materials and program descriptions that are available for coalitions to adapt or use. When the coalitions determine the cancer priorities and programs that are most relevant for their communities, NCALIC staff members will provide special training to support the development of specific interventions. Coalitions also may choose to develop their own materials, particularly those targeting hard-to-reach populations. NCALIC project staff members will supply resources and technical assistance to facilitate this process.

NCALIC will use demographic data to identify the population characteristics of the intervention area and to ensure that all groups are represented. The project's interventions specifically will target minorities, low-income residents, people with limited reading skills, and the medically underserved. Needs assessments will be essential for supporting and reinforcing priorities that communities have set for themselves. Coalitions will conduct community assessments to identify needs and barriers in their areas. Barriers might include limited access to medical care, child care, and transportation. Coalitions will use these findings along with cancer mortality data and incidence estimates to define the focus of their interventions.

NCALIC coalitions will develop networks of volunteers to help conduct intervention activities. Some volunteers will be members of affiliated community groups, such as those sponsored by ACS and CIS; others will be recruited from the community at large. NCALIC project staff will assist the coalitions in this process of recruiting, training, and motivating the volunteer network.

NCALIC's regional intermediaries will help the project identify communication channels that reach their counties. Local coalitions will have access to other, possibly less formal, channels. Each coalition will include a media representative who will be responsible for using all available channels. MBRCC, the Riverside Regional Cancer Institute, and key intermediaries will provide technical support by helping the coalitions to develop news stories and PSAs and to interact effectively with the media. Each coalition will prepare a dissemination plan to ensure that materials and program information reach the intended audience. Some materials will be disseminated directly from NCI, MBRCC, and key intermediaries.

NCALIC's rationale for using a menu based on NCI's priorities as well as materials developed or approved by NCI is that this approach provides coalitions with a wide range of opportunities within the defined parameters

of the project. Materials and adaptations developed by individual coalitions provide opportunities to establish ownership by creating products with a local identity. These locally initiated components may prove to be the most effective tools.

Project Evaluation

Each community coalition must gather data for measuring the success of its efforts. Regional coordinators will help the coalitions develop objectives, determine baseline and postbaseline data that will measure progress toward those objectives, and identify potential opportunities for obtaining these data. Coalition leaders will be trained to develop assessment tools based on generic forms and will receive ongoing technical assistance from NCALIC staff members to help develop process measures. Budget constraints probably will limit these measures to the level of cancer-related awareness. Coalition members with interest in a particular area, such as tobacco use, will be encouraged to take a key role in contributing to data collection in that area.

In addition to data collected by local coalitions, data that have been assembled by other agencies will be gathered by NCALIC. For example, the project will collect data on cancer mortality from state tumor registries, cancer-related risk behaviors from the Behavioral Risk Factor Surveillance System, and tobacco sales and use from state departments of tax and revenue. NCALIC also will gather data that are not yet assembled by agencies or other sources; for example, data on Pap test utilization will be obtained through annual surveys of pathology laboratories.

Process Evaluation

NCALIC will use several measures to document the extent to which vital and functioning coalitions are created within the project. Data necessarily will be collected primarily from self-reports by field staff and coalition members. Data from coalition members will be collected under the direction of the regional coordinators, using measures designed by NCALIC project staff with input from an evaluation specialist and coalition members. Most measures relating to methods that are used to form and structure coalitions will be generic (applying to all coalitions).

► **Methods used to form and structure coalitions:** Regional coordinators will initiate the development of coalitions throughout the region. NCALIC will assess specific details of the approaches used to enlist coalition members and to cultivate intermediaries and leadership for the local coalition. NCALIC also will gather subjective information on approaches that seemed to work best in particular situations.

► **Breadth of coalition membership:** NCALIC will examine the number of coalition members, the type of representation among members, and the extent to which individual coalition members become involved in the coalition.

► **Interaction patterns:** A variety of measures will be devised to gain insights into the styles of coordination and collaboration among various coalition members. NCALIC will examine the frequency of meetings, the formation of committees or other structures, and the characteristics of coalitions that were able to mount ambitious and well-conducted activities. These measures and characteristics will be compared with those of coalitions that were less able to implement cancer prevention and control activities.

► **Media coverage:** NCALIC will collect counts of materials with project messages that appear in the various media, including television, radio, newspapers, and magazines. Resulting media coverage for the overall project or individual coalition effort will be documented as a measure of program activity.

Although process measures relating to interventions conducted by the coalitions will have a generic core, they will be individual-

ized according to the selected activities of each coalition. The NCALIC project manager and regional coordinators will work with coalitions to formulate these measures, which will include an estimate of people reached and materials distributed as well as qualitative measures addressing the rigor of procedures, the attention to details, and the level of appropriate reviews. Strategies to nurture, sustain, and reinforce coalitions also will be sought. NCALIC hopes to identify strategies that are associated with satisfied and productive coalitions as well as those that are associated with coalitions that seem to flounder.

Outcome Evaluation

NCALIC has targeted four specific measures related to outcome evaluation.

► **Annual rates of cancer incidence and mortality as well as data on the stage at diagnosis:** County cancer rates—especially for cancers of the breast, cervix, lung, colon, and prostate—will help coalitions determine the cancers and related risk reduction behaviors that they should target.

► **Tobacco use:** NCALIC will determine the number of packs of cigarettes and units of smokeless tobacco products that are sold annually by monitoring available data from the departments of tax and revenue in West Virginia and Ohio. NCALIC also will monitor states' tobacco use as reported by CDC in BRFSS.

► **Cancer screening utilization:** NCALIC will track cervical screening activity through annual surveys of the pathology laboratories that perform cytological examinations of Pap tests. These data will be sought separately for screening tests and retests. NCALIC recognizes that a limitation to these data is the fact that laboratories may not be reading slides only from Appalachian counties and that some Appalachian counties may send slides elsewhere. NCALIC also will track mammography screening activity for each state. For example, the West Virginia Bureau of Public Health, through its Office of Health Facilities Licensure and Certification, inspects and tests all dedicated mammography machines in the state. At each inspection visit, the aggregate number of tests performed in the previous year is recorded. A limitation of these data is the fact that records do not distinguish between screening and diagnostic procedures. In addition, NCALIC expects that BRFSS will provide 1991 screening estimates based on survey questions regarding the length of time since respondents last had Pap tests and mammograms.

► **Diet:** NCALIC will access data on the Special Supplemental Food Program for Women, Infants, and Children (WIC) in the project's area through CDC's Pregnancy Nutrition Surveillance System. WIC educates low-income women to improve their food choices and to prevent a variety of acute and chronic illnesses, including cancer.

In addition, NCALIC will collect from individual coalitions outcome measures related to interventions. These data will be the sole outcome measures of individual coalitions' initiatives. NCALIC also will seek data regarding the costs and energy expenditures associated with various efforts of coalition groups.

Initial Planning Issues

NCALIC recognizes the limitations of developing and supporting coalitions across a large geographic area with limited staff and funds. The project must focus communities on cancer as a priority among other urgent competing issues, generate and sustain interest in cancer prevention and control coalitions, and respond to unanticipated community concerns. During its first year, NCALIC has hired and trained staff, developed criteria for selecting communities as sites for cancer prevention and control coalitions, identified regional coalition members, and planned how to evaluate an ever-changing project. NCALIC also has focused on ensuring the cooperation of major intermediaries in Ohio

Project Characteristics of the North Central Appalachia Leadership Initiative on Cancer

1. The North Central Appalachia Leadership Initiative on Cancer (NCALIC) will be conducted in West Virginia and Ohio by the Mary Babb Randolph Cancer Center (MBRCC), located at the University Health Science Center in Morgantown, West Virginia.

2. NCALIC will target mainly rural communities that are characterized by an aging population, low literacy and educational levels, and people of various ethnic descent.

3. NCALIC will conduct a series of educational training meetings to mobilize local leaders by familiarizing the community with the problem of cancer and how ALIC projects will address a particular related issue.

4. NCALIC will select and assess potential coalition communities; offer resources and technical support in response to cancer-related concerns; and build relationships at the state, regional, and local levels to nurture coalitions and document the process by which communities unite and act.

5. NCALIC will work toward enabling communities in West Virginia and Ohio to implement their own cancer prevention and control interventions.

6. NCALIC will attempt to change the way communities view health, teach individuals that they have more control over their health, change the expectations of patients and health professionals about the services they receive or provide, and encourage legislators to pass laws that improve access to cancer-related services.

7. NCALIC will help local coalitions with program planning, media relations, progress evaluations, and grant writing.

8. NCALIC will help local community coalitions conduct community assessments to identify needs and barriers, to utilize assessment findings along with other statistics, and to focus their interventions.

9. NCALIC will help recruit, train, and motivate volunteers to help conduct intervention activities.

10. NCALIC will use data gathered by community coalitions as well as other agencies to measure the success of their efforts. Outcome evaluations will be based on four specific measures:

    1. Annual rates of cancer incidence and mortality as well as stage at diagnosis;
    2. Tobacco use;
    3. Cancer screening utilization; and
    4. Nutrition.

11. NCALIC will collect information about the methods used to form and structure coalitions, breadth of coalition membership, interaction patterns, and media coverage to document the extent to which vital and functioning coalitions are created within the project.

and West Virginia and on determining the reading comprehension levels of rural, low-income individuals in the project's area.

NCALIC already has learned the value of input from local leaders and the use of regional history in understanding the perspective of a community. NCALIC also has found that it will need to address the problems that scientifically trained evaluators are expected to encounter while working on the project.

NCALIC intends to rely on MBRCC's knowledge of NCI priorities and resources as well as the center's established linkages with other NCI- and CDC-funded projects, ACS, and state health departments. NCALIC will use these connections to integrate its activities into existing coalitions as well as to build new coalitions in West Virginia and Appalachian Ohio. NCALIC will be concerned particularly with the strategies used by the coalitions that are the first to stimulate interest in cancer prevention and control activities in other areas of the states.

Although NCALIC will use scientifically based methods to determine the extent to which it meets specific goals and objectives, it also views the challenge it faces in a simpler way. According to many rural West Virginians, if you think you are sick, there are ten steps to follow.

1. Think of your mother's advice.
2. Talk to your mother.
3. Talk to your mother's closest female relative.
4. Talk to close female friends.
5. Try an over-the-counter remedy that you saw on television.
6. Go to the drugstore and ask advice from the pharmacist.
7. Go to the county health department and ask advice from the nurse.
8. Go to a health clinic.
9. Go to the emergency room at the local hospital.
10. Go to a big city hospital.

NCALIC believes that if it can intervene during any of the first nine steps, it can keep people from reaching the last step.

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CHAPTER 13

Central Highlands Appalachia Leadership Initiative on Cancer

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Instituitional Context

The Lucille Parker Markey (LPM) Cancer Center at the University of Kentucky will conduct an Appalachia Leadership Initiative on Cancer (ALIC) project in 107 of the 120 Appalachian counties in Kentucky, Tennessee, and Virginia. The LPM Cancer Control Program will collaborate with three other university-based programs working in the region: the University of Kentucky's Center for Rural Health in Hazard, the James H. Quillen College of Medicine/School of Nursing at East Tennessee State University in Johnson City, and the Department of Community Health Education at Virginia Polytech Institute and State University in Blacksburg (Virginia Tech). From this core group, the Central Highlands Appalachia Leadership Initiative on Cancer (CHALIC) has established linkages to the following entities in all three states: state, district, and local health departments; American Cancer Society (ACS) affiliates; area health education centers (AHECs); Cooperative Extension Services (CESs); state primary care associations; regional medical centers; community colleges and regional colleges; local development districts (LDDs); and grassroots activist and community development organizations. As with the other ALIC project award institutions, the Central Highlands project represents for the LPM Cancer Center a new program based on related and preceding efforts in cancer prevention and control. In conjunction with the Brown Cancer Center at the University of Louisville in Kentucky, the LPM Cancer Control Program has designed and implemented Kentucky's statewide cancer control program, the Kentucky Cancer Program (KCP). This program, which serves as a model for the Central Highlands project, has three active components: Community Programs Division, Kentucky Cancer Information Service, and Kentucky Cancer Registry.

The primary concerns of the Community Programs Division are public and professional education. Educational planning and program activities are implemented through KCP's special network of 15 District Cancer Councils (DCCs). Each DCC has 20 to 40 professional and lay members from counties within its district and in most cases represents such entities as local divisions of the American Cancer Society, local health departments, county extension agencies, local hospice programs, local clinics and hospitals, patient support groups, and local civic and grassroots organizations. These councils receive support services from nine regional coordinators in offices spread across the state. The coordinators present many programs each year to schools, civic clubs, industries, senior citizen groups, and the general public.

The Kentucky Cancer Information Service operates the toll-free 1-800-4-CANCER telephone line supported by the National

Cancer Institute for Kentucky. To reach many of the adults it serves, the Cancer Information Service and the Community Programs Division have formed a Cancer Literacy Coalition in eastern Kentucky. KCP personnel, local literacy council directors and tutors, local health department personnel, university consultants on rural health, and various others have produced interactive educational modules concerning screening for breast and cervical cancers. These materials will form part of the regular curriculum of literacy training programs in eastern Kentucky.

The Kentucky Cancer Registry, which is housed at the University of Kentucky, was established in 1990 as the official state registry when the General Assembly passed legislation mandating that all 109 acute care hospitals and freestanding cancer treatment centers in Kentucky report cancer incidence, stage at diagnosis, and case management to the registry. The registry will make it possible to measure changes in the stage at diagnosis for different cancers over time and to indicate geographic and demographic patterns of cancer incidence, diagnostic approaches, and case management in the state. This information will provide data and maps on which public and professional cancer educational efforts sponsored by CHALIC can be based.

The East Tennessee State University (ETSU) College of Medicine and School of Nursing has developed extensive programs for training physicians and nurses for service to rural communities by making health profession students aware of the needs of rural Appalachian communities. One of these needs is cancer prevention and control, with special regard to the relatively high mortality of cervical cancer and lung cancer in this region. In 1990, the ETSU Department of Family Medicine established a community-oriented primary care clinic as a rural training site for students and residents while simultaneously addressing the severe health care needs of Johnson County. In direct response to expressed community needs, the ETSU School of Nursing opened its Extended Hours Family Health Center in Mountain City, with extensive community and state input and support. Health promotion and screening activities are integral parts of clinic services, including the recent initiation of a special women's health screening "package" available to clients.

A cooperative effort by the Hancock Medical Clinic (part of the Rural Health Services Consortium clinic system), the ETSU School of Nursing, the Hancock County Agency on Aging, the Hancock County Public Health Department, and Nolichucky Mental Health Services resulted in the award of a Health Resources and Services Administration grant to fund health-related outreach activities to residents of Hancock County, the second poorest county in the nation. Age-appropriate screenings for breast, cervical, prostate, testicular, and colorectal cancers are part of the services available. In the first quarter of 1992, more than 700 people visited the health center for various screenings, including health risk appraisal and individualized lifestyle counseling.

An innovative cooperative program being developed by ETSU is sponsored by the W.K. Kellogg Foundation as part of its Community Partnerships with Health Professionals Education Program. ETSU's Division of Health Sciences (School of Nursing, College of Medicine, and School of Public and Allied Health) was awarded a grant in 1991 to develop new interdisciplinary programs for relocating significant portions of the health professions curricula to rural community settings and for developing, in partnership with community leaders, new educational content and methods for involving students with communities. As part of this large multifaceted project, community advisory boards have been formed in each of these rural communities. These boards are undergoing a process of leadership development and could form the basis for some of the pilot local community cancer

control activities proposed in the current grant application.

The Tennessee Division of the American Cancer Society has formed a Task Force on Cancer Among the Economically Disadvantaged in many of its county units or districts. Although activities vary somewhat among the units, all units have agreed to focus initially on lung and breast cancers. In one unit, an effort is being made to use churches as centers of information distribution and cancer screening; in another, flyers are being prepared for distribution through local supermarkets. Development of appropriate materials for low-literacy segments of the populations is a recognized need.

The Department of Community Health Education at Virginia Tech has been active in the Health Promotion and Education Council of Virginia, which represents more than 24 public, private, and nonprofit statewide organizations committed to promoting health for children, the elderly, minorities, rural residents, and other populations at risk of developing preventable diseases or injuries. Within this context, the council is working to decrease cancer morbidity and mortality.

Reducing the incidence of preventable death and disability in the Commonwealth of Virginia is one of three priority goals of the Virginia State Board of Health. The Office of Health Education and Information (OHEI) now plans to address cancer control within a more comprehensive chronic disease prevention program. OHEI recently has placed health educators with master's degrees in demonstration projects in four health districts in the CHALIC project area—Cumberland Plateau, Mt. Rogers, New River, and Alleghany. The health educators are involved in diet modification and smoking prevention and cessation activities in communities and workplaces. These teachers may be pivotal in organizing and maintaining health-focused coalitions in their districts.

In 1991, the National Cancer Institute (NCI) awarded Virginia a 7-year grant to conduct an American Stop Smoking Intervention Study for Cancer Prevention (ASSIST). The long-term goal of ASSIST is to reduce smoking prevalence in the total population to 17 percent or less by the year 1998 and to reduce the initiation of smoking among youth by 50 percent by the year 2000. Managed by OHEI and ACS, ASSIST is a coalition-driven project with numerous representatives from the CHALIC project area. In a similar way, the Blue Ridge School Health Education Conference, held annually for the past 10 years, provides an opportunity for school personnel teams (e.g., teachers, administrators, food service workers, nurses) from school districts to learn about healthy lifestyles for a week each summer and to develop a health promotion plan that they will implement at the beginning of the school year. This program has played an important role in diffusing health promotion and risk reduction information and education to school employees and students throughout the state.

The State Office of Epidemiology supports the Virginia Tumor Registry and chronic disease surveillance activities within the Virginia State Department of Health. The registry has collected cancer data on a voluntary basis since 1970; in 1990, the legislature mandated reporting, and the 1992 data should show 100-percent coverage. Block grant funding enabled Virginia to join other states in 1989 in implementing the Centers for Disease Control and Prevention's ongoing Behavioral Risk Factor Surveillance System (BRFSS).

The Alive and Well Coalition of the Roanoke Valley (Alleghany and Roanoke City Health Districts) received a Project LEAN award from the Henry J. Kaiser Family Foundation. Project LEAN is a national nutrition education campaign to help people reduce their dietary fat consumption, a risk factor for colon cancer. Active since 1987 with more than 2,000 members, the coalition promotes lay and professional interest in health

promotion and risk reduction, especially encouraging people to stop tobacco use, lose weight, and exercise. The coalition works with health service providers and grassroots leadership to plan and coordinate risk reduction activities such as "Quit and Win" contests.

Populations to be Served

Serving Appalachian areas of Kentucky, Tennessee, and Virginia, CHALIC is the most rural of the four ALIC projects, with 78 percent of its counties classified as rural (Figure 1 in Introduction to Section III). The median age of the counties' residents and the proportion of them 65 and older have shifted over the last decade. The proportion of residents currently 65 and older in the Appalachian portions of Kentucky, Tennessee, and Virginia is 12.5 percent, 13.7 percent, and 14.6 percent, respectively. This compares with 12.6 nationally (Appendix A).

Research has shown that in nonindustrialized countries, populations with the lowest literacy rates have the poorest health status, and similar research in the CHALIC area suggests that educational attainment also may be correlated to health status. Although the educational attainment of residents of the CHALIC region has improved significantly during the past 10 years, the seriousness of the problem remains evident. In 1990, the proportion of adults age 25 or older with a high school diploma was only 51.5 percent for Appalachian Kentucky, 63.9 percent for Appalachian Tennessee, and 56.4 percent for Appalachian Virginia. These figures compared with 75.2 percent nationally (Appendix A).

Common Characteristics of CHALIC Communities

In addition to a common border, the CHALIC states share a similar geography and climate: hot, humid summers; cool, wet winters; glorious springtimes; and colorful autumns. The central region of Tennessee and Kentucky, bordered by great rivers and containing the most fertile soil, remains the most prosperous region of the area.

The first white settlers in Kentucky, Tennessee, and southwestern Virginia came in search of land, opportunity, and independence. All three states were battlegrounds during the Civil War, and each has coped with the bitter legacies of that conflict, including delayed economic development, defensive regionalism, and strained race relations. The Appalachian areas of each state share a similar culture, outlook, and accent. Rural life remains an important characteristic of the region, and family and church are important to residents. The states also share similar urban problems with larger cities such as Knoxville and Chattanooga.

Many other interesting characteristics define the region. The boom-and-bust cycles of the coal industry are common to Kentucky and Virginia. In addition, college basketball is a force that both unifies and divides the region. Kentucky, Tennessee, and Virginia all grow tobacco, whose impact on the health and economy of the region cannot be ignored.

Too many people in the region die from cancer, especially lung cancer. Many are poor, and many lack adequate literacy skills. However, poverty, literacy, and cancer serve as a common target, and the states' shared history and culture provide a common ground on which to organize effective ways to address these problems.

Incidence and Risk of Cancer

Available mortality data for the region served by CHALIC indicate that rates for some cancers are higher than overall U.S. rates. Moreover, the mortality rates of other cancers are increasing faster than overall U.S. rates.[1] Table 1 shows the average annual age-adjusted cancer specific mortality rates for the 120 Appalachian counties in Kentucky, Tennessee, and Virginia (the CHALIC project area will target 107 of the 120 counties) and the corresponding mortality rates for the United States.

TABLE 1

CHALIC project area compared with the U.S. average annual age-adjusted mortality rates for lung, cervical, breast, and colorectal cancers per 100,000 population, 1963-1987

Cancer Site	1963-1987 CHALIC Mortality Rate	1963-1987 U.S. Mortality Rate
Lung (males and females)	39.39	37.85
Lung (males)	70.04	64.63
Cervical (all females)	7.83	6.02
Cervical (white females)	7.79	5.26
Breast (all females)	19.94	26.59
Breast (nonwhite females)	23.99	24.13
Colorectal (males and females)	16.37	22.38

Source: Release 8.3 of Mortality Analysis from NCI and the Centers for Disease Control and Prevention.

Mortality rates for lung and cervical cancers are higher in the CHALIC area. The male lung cancer mortality rate in the area is much higher than the U.S. rate. Most of the people living in the Appalachian areas of Kentucky, Tennessee, and Virginia are white. The cervical cancer mortality rate among white females in the area is substantially higher than the U.S. rate for white females. In contrast, the female breast cancer mortality rate in the CHALIC area is lower than the U.S. rate. However, the female breast cancer mortality rate among nonwhites in the CHALIC area is nearly equal to that of the U.S. rate. In addition, the overall female breast cancer mortality rate in the CHALIC area has been rising much more rapidly than the female breast cancer mortality rate in the United States, as shown in Figure 1.

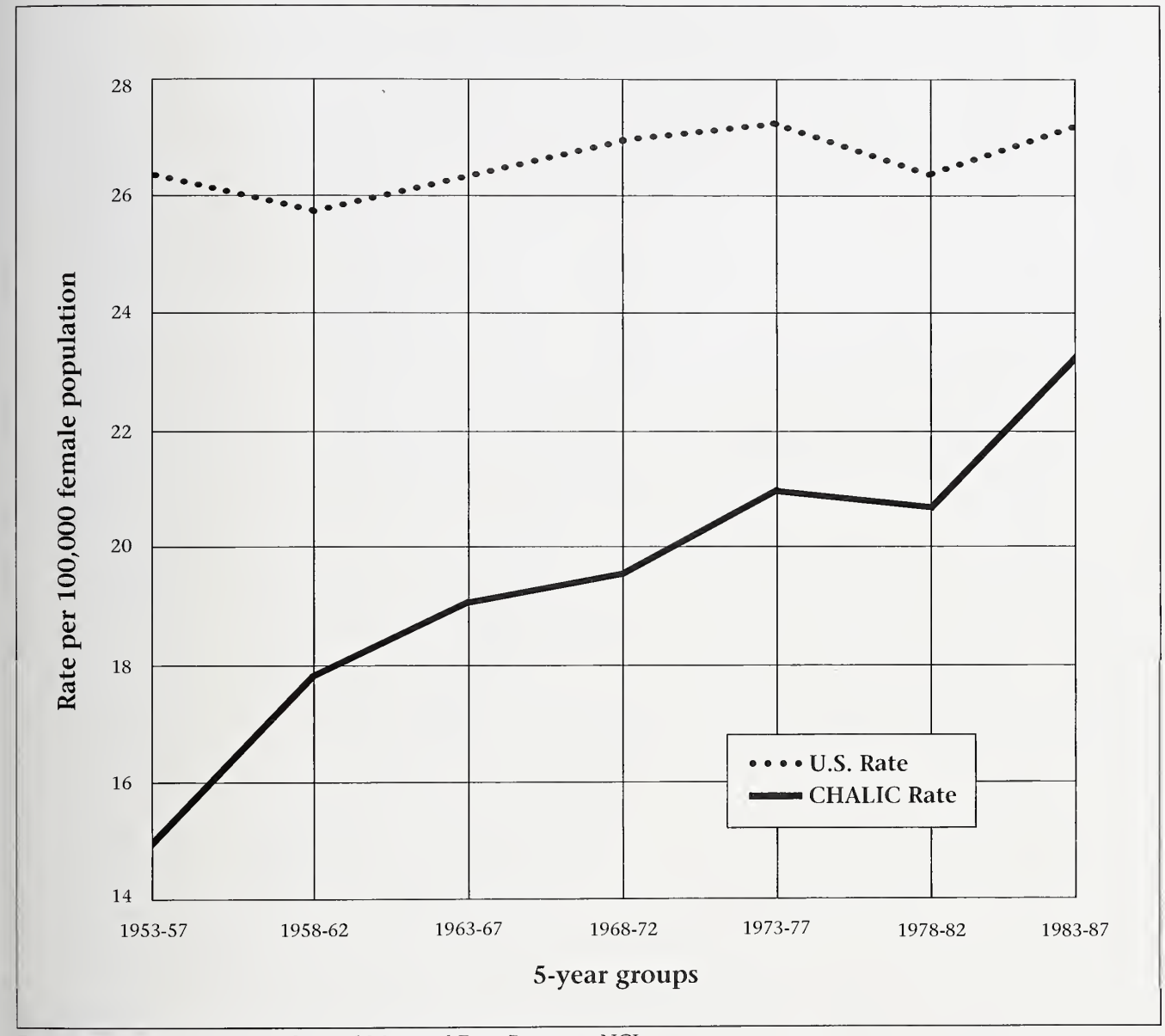
The higher mortality rates for some cancers among residents of the 120-county area of Central Highlands Appalachia compared with those of the U.S. population may be related to poverty (see Chapter 7 of this monograph). Behaviors, such as high levels of tobacco use for both males and females, coupled with a lack of information regarding risks and symptoms of cancer, plus limited access to health care or delayed utilization, may produce a persistent disadvantage for cancer occurrence and survival once the disease is diagnosed.

Mobilizing Leaders

CHALIC's strategy for mobilizing and recruiting lay and professional leaders is similar to that of the North Central Appalachia Leadership Initiative on Cancer in that it solicits the recommendations of potential coalition members through tiers of linkages with state, regional, and local organizations. CHALIC has established the foundation for its networking strategy with four university-based programs: Lucille Parker Markey Cancer Control Program at University of Kentucky; Center for Rural Health at University of Kentucky; James H. Quillen College of Medicine and School of Nursing at East Tennessee State University; and Department of Community Health Education at Virginia Polytech Institute and State University.

From this base, CHALIC has forged formal linkages with organizations at all levels in

Figure 1. CHALIC project area compared with U.S. average annual age-adjusted mortality rates for female breast cancer, 1953-1987, 5-year intervals



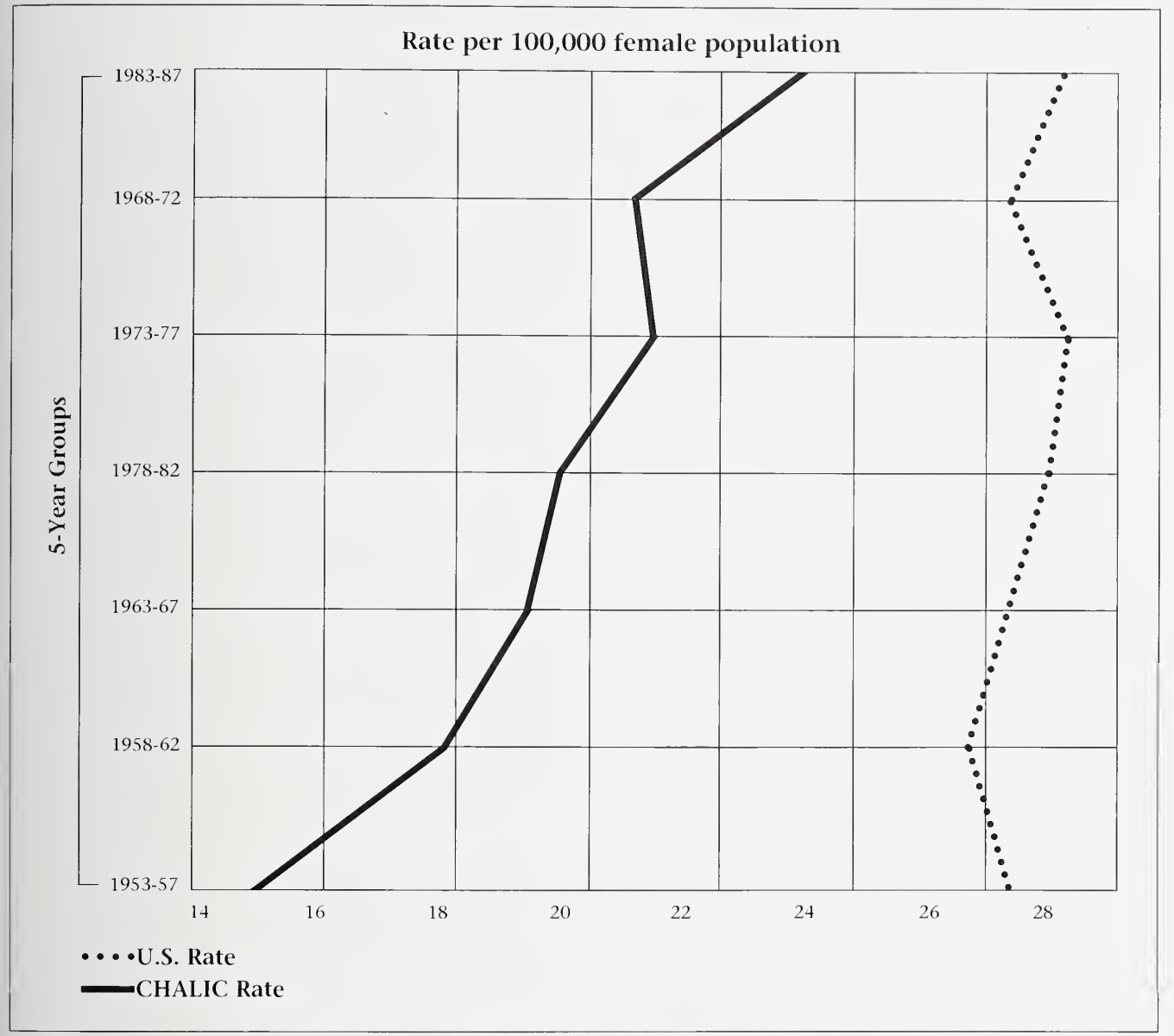
Data Source: State Cancer Control Map and Data Program, NCI.

Kentucky, Tennessee, and Virginia. As noted earlier, these groups include state, district, and local health departments; ACS divisions; AHECs; Cooperative Extension Services; state primary care associations; regional medical centers; community colleges; regional colleges; local development districts (LDDs); and grassroots activist and community development organizations.

This second tier of linkages will provide input regarding the identification and recruitment of 10 to 15 individuals from each of the 15 politically designated LDDs that constitute the CHALIC region. These LDDs originally were created by the Appalachian Regional Commission as multicounty area planning and development districts. Potential participants will be identified through two methodologies:

▶ Compiling the names and occupations of individuals in each district who occupy key positions in the major social, economic, political, governmental, religious, and health-related institutions, including both formal and

Figure 1. CHALIC project areas compared with U.S. average annual age-adjusted rates for female breast cancer, 1953-1987, 5-year intervals



Data Source: State Cancer Control Map and Data Program, NCI, **date**

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► Compiling the names and occupations of individuals in each district who occupy key positions in the major social, economic, political, governmental, religious, and health-related institutions, including both formal and

grassroots voluntary organizations and associations; and

► Interviewing knowledgeable persons within each LDD and compiling a list of local individuals who by reputation have the power and influence to affect the outcome of many communitywide issues, especially those related to health.

Members of CHALIC's advisory committees will assist district coalition members in recruiting and mobilizing 200 to 250 community leaders, who will form the core support for 40 to 60 community leadership groups within the 15 LDDs.

One of CHALIC's challenges is to launch successful cancer control activities based on the region's commonalities. The project's efforts to accomplish this goal will require research designed to answer the following questions:

► How does the current (1992) "system" of cancer control activities in the CHALIC region support community-oriented health projects, efforts by community coalitions to improve the health of their communities, efforts by interagency consortia to improve the health status of disadvantaged populations, and efforts by disadvantaged populations to improve their own health status?

► What would constitute a future (1997) ideal "system" of cancer control activities, which would support the efforts of community-oriented health projects, community coalitions, interagency consortia, and formal and informal groups from disadvantaged populations to improve the health status of their own communities? How would this system work?

► What feasible and cost-effective changes would be required to develop the current system into the future ideal system?

► How can CHALIC facilitate these changes?

Building a Network of Coalitions

The Kentucky Cancer Program, a joint effort of the University of Kentucky and the University of Louisville, has organized statewide community cancer control efforts successfully through a university-based, community-oriented approach that uses LDDs as its basic unit of organization and planning. CHALIC's strategy for building a network of coalitions is based on the Kentucky Cancer Program's approach. As previously discussed, 10 to 15 individuals from each of the 15 LDDs will be recruited and mobilized to address the unique cancer problems in their communities. These individuals, in turn, will promote and support the development of three to four community coalitions or leadership groups in each district. Figure 2 illustrates CHALIC's organizational structure.

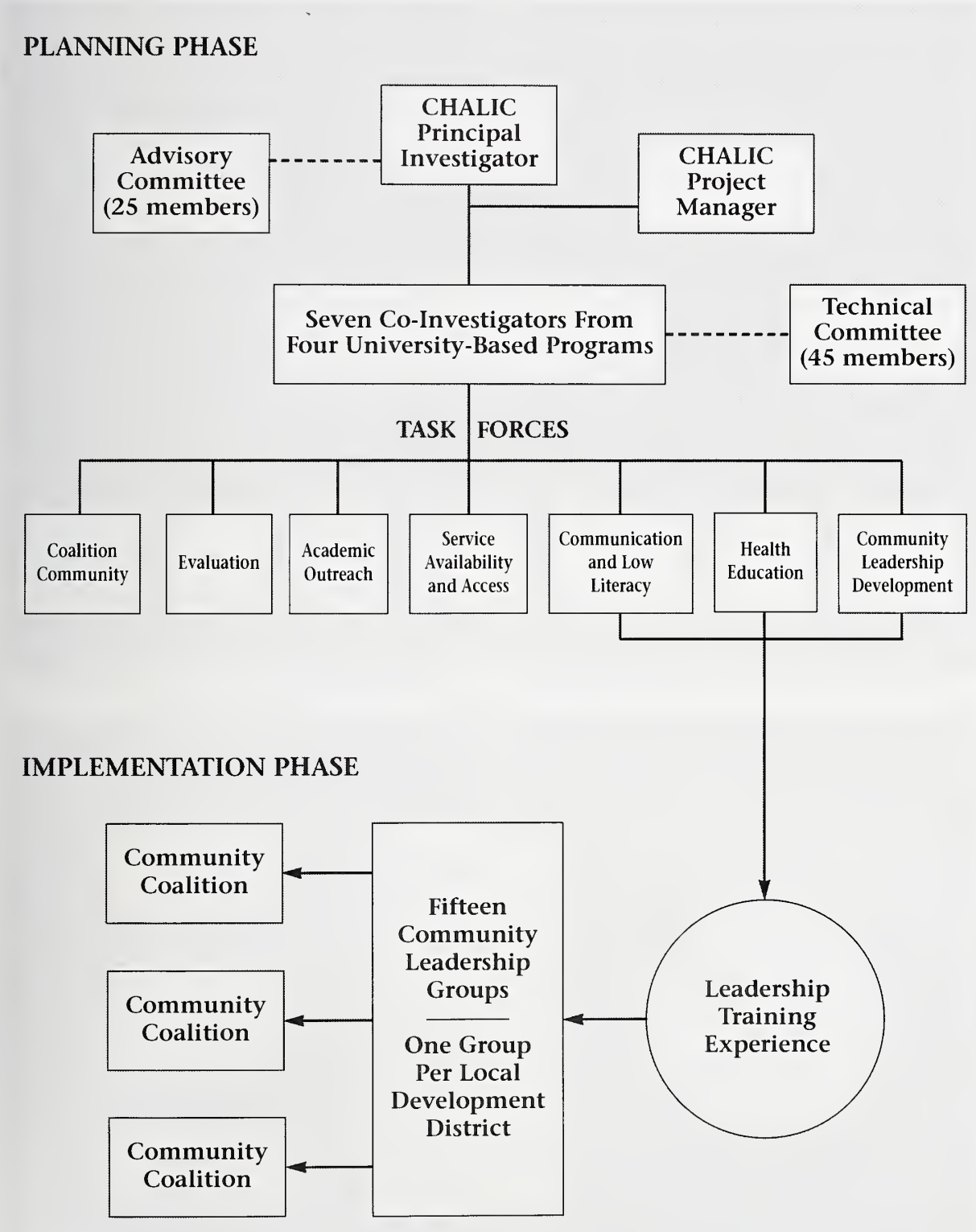
These 40 to 60 community leadership groups will design and implement local cancer control outreach activities, using resources from a variety of public, private, and governmental organizations. Their efforts will be supported by CHALIC staff members and the four university-based programs as well as by other individuals in organizations that have established formal linkages with CHALIC.

In addition, several committees will provide direction and advice for CHALIC. An advisory committee composed of approximately 25 well-known and respected persons will meet once a year. CHALIC already has established a technical committee comprising approximately 35 lay and professional leaders actively involved in cancer control outreach efforts or other population-based and community-oriented approaches to preventive health care. The technical committee will participate directly in the development of the implementation plan during the first year. The task forces will focus on specific needs or concerns of the CHALIC project, such as health education, services availability and access, academic outreach development, community leadership development, communication and low literacy, coalition continuity, and evaluation.

During CHALIC's first year, persons selected from each of the 15 LDDs will attend an ori-

TABLE 1

CHALIC project organization



entation meeting and subsequent workshop. These sessions are designed to help participants analyze the specific cancer problems or issues affecting their communities and develop community leadership groups to address these problems.

As these groups are established, curricula developed by the task force on community leadership will be used to train local members. Additional support and ongoing technical assistance will be provided through local health department staff, county extension agents, ACS volunteers, and LDD staff members. Special efforts will be made to form groups that represent African-American populations, which are centered in and around the two urban centers of Knoxville and Chattanooga. Additional support for community leadership groups targeting this special population will come from the East Tennessee AHEC and the National Black Leadership Initiative on Cancer, which have staff members and volunteers working in eastern Tennessee.

CHALIC is adapting the Kentucky Cancer Program model to the broader needs of ALIC, which seeks to develop rural models of community organization or coalition building that are not restricted to current health care delivery networks. CHALIC planners realized that, although the Kentucky model had decentralized the two universities' cancer control outreach activities significantly, the membership of its district cancer councils was dominated primarily by health care providers and cancer patients and survivors. These members were less likely to live in the most rural counties and less likely to represent poor, minority, and medically disadvantaged populations. Furthermore, although the Kentucky model encourages a community-oriented approach to program planning for cancer control outreach activities, the very composition of district cancer council memberships and the strong influence exerted by regional medical centers often created a client-based approach to community health promotion for cancer control rather than the population-based approach essential to CHALIC's work.

Population-based approaches include any intervention that deals with an entire population rather than a self-selected group of persons who present themselves for clinical services. Community-oriented approaches include any intervention that has been developed by a planning process that involves the community in all phases, including needs assessment, development of specific activities, and evaluation. Inherent in these approaches is the need for leadership development.

The development of community leadership groups within the districts is intended to decentralize cancer control outreach activities further and to extend CHALIC coalition membership beyond health care providers to members of grassroots organizations. This broader and more decentralized participation should help ensure that CHALIC program planning and cancer control outreach activities are influenced not only by a client-based approach but also by population-based and community-oriented approaches to health promotion and preventive health care.

Developing and Disseminating Intervention Programs and Strategies

Community leadership groups representing each of the geographic areas throughout the CHALIC region will be asked to review data about the cancer incidence, mortality, and associated risk behavior rates within the area. These data for each county or cluster of counties will be compared with similar data for the CHALIC area as a whole as well as with state, regional, or national data. The leadership groups also will be asked to develop and implement cancer control intervention strategies based on the review of the data specific to each group's area. In addition, the groups will be asked to participate in cancer control studies in which CHALIC communities with lead-

ership groups will be paired with other CHALIC communities without leadership groups (i.e., control communities). If enough community leadership groups are formed, CHALIC may be able to conduct cancer control experiments in which communities are allocated randomly to experimental and control groups.

The actual intervention strategies to be tested will be selected during CHALIC's planning phase. One possible intervention strategy involves the recruitment and training of women from communities that have formed leadership groups. These women would seek out and help socially isolated women to enter public health clinics for cervical cancer screening. Communities willing to conduct this intervention might be paired with communities that will not conduct the intervention. The percentage change in the number of Pap tests performed before and after the intervention could be compared between experimental and control communities. Whenever statistically significant changes are identified, CHALIC will attempt to implement the associated intervention in the control communities and to determine whether significant changes subsequently occur in the control communities.

The consensus of the technical and advisory committees after the first-year planning phase will provide the parameters for most CHALIC interventions. Because the project emphasizes community ownership at the district and local levels, it will provide mechanisms to modify and amend interventions and strategies based on feedback from those levels.

Meetings of the technical committee and its state subcommittees already have revealed concerns about the difficulty of developing community coalitions focused exclusively on cancer issues. Consequently, CHALIC plans to accept a broader definition of community health promotion. For example, the First International Conference on Health Promotion held in Ottawa, Canada, in 1986 defined health promotion as a process that enables people to take control of their lives by improving their health. Conference participants identified five overlapping and interactive means of action: building public health policy, creating supportive environments, strengthening community action, developing personal skills, and reorienting health services. CHALIC believes that adopting this broad framework for community health promotion will allow the project to assist communities in organizing themselves around issues that are relevant, meaningful, and practical for them.

Project Evaluation

CHALIC will collect data routinely to assess the effectiveness of the project and its intervention strategies. The project will gather data on cancer incidence and mortality, as well as stage at diagnosis, from the cancer registries of the three states in the CHALIC region. Data on the cancer-related knowledge, attitudes, and behavior (KAB) of people living in the region will be collected from BRFSS. CHALIC will use several sources to obtain information on health risk behaviors at community levels. As an alternative to local KAB surveys, CHALIC will use data on tobacco taxes collected by each state to estimate tobacco use. Local health department records of Pap tests and data from mammography facilities will help CHALIC measure changes in the use of cancer screenings.

Process Evaluation

CHALIC staff members will document processes of the overall project and each individual coalition during planning and implementation phases. CHALIC will collect the following types of process information:

- Composition of coalitions, including form, structure, and extent to which the diversity of persons involved reflects the diversity found within the community;
- Number of people participating in leadership training sessions;

► Comparison of district coalitions and community leadership groups to identify factors that influence the formation and development of coalitions;

► Interaction patterns, including the frequency and type of communication, strategies for conflict resolution, and actors involved in cooperative activities;

► Maintenance activities, such as the level and type of encouragement needed to maintain interest in the coalition;

► Number of community residents who participate in the development of local community action or research projects; and

► Factors that contribute to the selection of sound and feasible targets for intervention, the comprehensive assessment of community needs, and the creation of detailed and realistic plans.

CHALIC is particularly interested in processes that broaden the base of community leadership for cancer prevention and control.

Outcome Evaluation

During CHALIC's first year, an evaluation task force will develop an evaluation plan with input from the technical and advisory committees. The actual intervention strategies will be developed during the second year of the project. Cancer mortality rates in the CHALIC region indicate the need for cancer control interventions that target cancers of the lung, cervix, breast, and colon. Based on these target cancer sites, CHALIC can identify some baseline measures that will be used to determine changes (outcomes) that occur following the implementation of cancer control intervention efforts.

During the first year of the project, CHALIC will refine these measures and gather data to serve as baselines for assessing future changes. Outcome measures will include incidence rates, age-adjusted incidence rates, and stage-specific incidence rates for the target cancers in each county within the CHALIC region. The early stage-specific rates preceding an intervention will be compared with the same stage-specific rates following a cancer control intervention. Other outcome measures include knowledge, attitudes, and behaviors based on BRFSS data collected through state health departments. During CHALIC's first year, efforts will be made to apply BRFSS data from the three states specifically to the CHALIC area. One potential problem with the BRFSS data is that they exclude people who do not have access to a telephone. CHALIC will evaluate this issue carefully, using data from the 1990 census regarding the proportion of people in each CHALIC county who do not have telephones. Although the BRFSS sample sizes are small, it is believed that the survey data will serve as a baseline measure of cigarette smoking, knowledge about the Pap test and mammograms, and frequency with which Pap tests and mammograms are obtained throughout the CHALIC region.

Health risk behaviors at the community level also will provide outcome measures. Because the BRFSS sample size is too small to obtain community level information, CHALIC will access local sources to estimate utilization rates at the local level. Alternatives to local KAB surveys of self-reported health behaviors include estimating cigarette and smokeless tobacco use by obtaining the number of cigarettes and smokeless tobacco products sold in each county. This number will be based on tobacco tax data available at the county level from each state. These data can be used to calculate baseline consumption rates within each county. CHALIC can calculate the statistical changes in population-based consumption rates following the implementation of intervention programs. In addition, CHALIC can estimate the change in cervical cancer screening among women in poverty who are encouraged or guided to obtain a Pap test from their local health department; this can be accomplished by accessing health department records regarding the number of Pap tests performed. CHALIC also can estimate changes in

mammography screening following cancer control interventions by establishing a baseline measure of the number of mammography sites and the number of mammograms performed throughout the CHALIC region.

During the planning phase of the project, CHALIC will identify other utilization data that can serve as baseline measures for health behaviors. Data on these measures will be used to determine changes following the implementation of cancer control interventions. In addition, CHALIC will attempt to determine the cost of each intervention strategy that is implemented and to develop a cost-benefit ratio. The benefit determination will be based on factors derived from both the process and outcome evaluations.

Initial Planning Issues

During its initial planning stage, CHALIC has had to face several issues. The most obvious issue that emerged from meetings of the technical committee and other groups interested in the project is the desire to know exactly what interventions are planned, when they will begin, and what resources will be available at the local and regional levels to implement them. NCI's commitment to support nearly a full year of planning and developing interventions from a constituency of active and informed communities initially was not readily accepted by some groups. This reservation may arise in part from the tendency of individuals and organizations already involved in cancer control to want immediate action. They do not always see the need for additional networking, community needs assessment, or prioritizing intervention strategies. Those unfamiliar with cancer control tend to prefer less planning and more definition and direction during the implementation phase of the project.

Differences emerged between participants with clinical or health education backgrounds and those more representative of community or grassroots activist organizations. The former group appeared to be more comfortable with CHALIC's focus on issues of lifestyle and personal behavior, such as tobacco use and diet. The latter group felt that issues involving the larger environment, such as environmental pollution and work-related hazards, were more conducive to building community coalitions. The second group believed that, given the project's emphasis on disadvantaged populations, too narrow a focus on the "lifestyle" factors could be construed as blaming the victim.

Defining "community" was also difficult. The CHALIC region covers a diverse population and a variety of political economies, including small farm agriculture, mining, lumber industries, national forests, rural manufacturing, urban manufacturing, and public assistance and transfer payments. Thus, a community may be a town or a county but also could be a factory, a local chapter of the United Mine Workers of America, or the local school system. During the second meeting of the CHALIC technical committee, members reached a consensus that CHALIC will define "community" in a broad and flexible manner. Thus, a community may be a kinship network; a hollow or valley; a village, town, or city; a workplace; a common place where consumers seek a product or a service; a civic or grassroots organization; or, most definitely, a county.

The history of the central highlands suggests that the term coming closest to including all these settings and categories may be "homeplace." To mountaineers, homeplace connotes family and birthplace; neighbors and an extended family of cousins, aunts, uncles, and grandparents who live just down the road; a sense of place beyond the name of a town or a county; and a certainty that one knows exactly where he or she will be buried.

One of the problems that the CHALIC project has encountered during its planning stage also can be viewed as one of the unique distinctions between CHALIC and the other ALIC

projects. Although all four ALIC projects propose to develop and encourage matrix coalitions that encompass a variety of traditional health-related organizations and nontraditional community-based entities, the other three projects plan to use some designated key players, such as Cooperative Extension agents, ACS volunteers, Cancer Information Service staff, and state health department officials. The other projects propose to use menus of pretested strategies, programs, or materials that in some ways may predetermine (or at least place some constraints on) the ultimate directions of their projects. CHALIC designates no one entity as a "key player"; in fact, the four university-based programs that constitute its core have only a geographic mandate by state to attract as many "players" as possible. These four programs plan to attract potential participants by offering them an opportunity to discuss problems affecting their communities rather than a preselected menu of interventions. In this way, CHALIC hopes to enlist a broad base of community support for and participation in local cancer control efforts.

Note

1. In an effort to begin developing an understanding of cancer within the CHALIC project area, average annual age-adjusted cancer mortality rates for 1953 through 1987 were calculated. Specifically, these mortality rates were calculated for lung, cervical, breast, and colorectal cancers using data from the cancer mortality mapping program developed by Pommerenke and colleagues (in press) for NCI and the Centers for Disease Control and Prevention (CDC).

Reference

Pommerenke, F.A.; Miller, R.W.; Srivastava, S.; and Ackermann, S.P. Targeting state and local cancer control: A place to start. *American Journal of Public Health*, in press.

Project Characteristics of the Central Highlands Appalachia Leadership Initiative on Cancer

1. The Central Highlands Appalachia Leadership Initiative on Cancer (CHALIC) will be conducted by the Lucille Parker Markey Cancer Center at the University of Kentucky in collaboration with the University of Kentucky's Center for Rural Health, James H. Quillen College of Medicine/School of Nursing at East Tennessee State University, and the Department of Community Health Education at Virginia Polytechnical Institute.

2. CHALIC will serve Appalachian areas of Kentucky, Tennessee, and Virginia. Many of these regions are rural with older residents with lower literacy rates, educational attainment, and income levels than other citizens.

3. CHALIC will recruit coalition members from a network of state, regional, and local organizations including state and local health departments, American Cancer Society divisions, area health education centers, Cooperative Extension Services, state primary care associations, regional medical centers, university-based programs, local development districts, and grassroots activists and community development organizations.

4. CHALIC will form a network of coalitions by recruiting and mobilizing 10 to 15 individuals from each of the 15 local development districts to address cancer problems in their districts and to develop and support three to four community coalitions in each district.

5. CHALIC will assist coalitions to do the following:

—Review data about cancer incidence, mortality, and associated risk behavior rates in their area;

—Compare county data with data from the entire CHALIC region;

—Develop and implement cancer prevention and control intervention strategies; and

—Participate in cancer prevention and control studies.

6. CHALIC staff will conduct process evaluation to document processes of the overall project as well as progress of each individual coalition during planning and implementation phases.

7. During the first year of the program, CHALIC will develop an outcome evaluation plan that will include such measures as incidence rates, age-adjusted incidence rates, and stage-specific incidence rates, as well as measures of knowledge, attitudes, and behaviors. CHALIC will help local coalitions collect these data.

8. CHALIC will offer potential participants the opportunity to discuss problems affecting their communities and to design appropriate interventions.

CHAPTER 14

Southern Appalachia Leadership Initiative on Cancer

Barbara K. Garland, Nolo Martinez, and Gale Harris

Institutional Context

The North Carolina Cooperative Extension Service at North Carolina State University in Raleigh, in association with Cooperative Extension Service (CES) programs at the University of Georgia and Clemson University, will direct the Southern Appalachia Leadership Initiative on Cancer (SALIC) project in the Appalachian portions of North Carolina, Georgia, and South Carolina. This work will continue past efforts of each state's extension service programs and will address the national agenda of CES, a program of the U.S. Department of Agriculture (USDA). Of nine national priority areas identified for fiscal year 1994 by the USDA's National Extension Committee, health care was accorded the highest priority. Moreover, the committee recommended collaborative efforts to address health issues.

Cooperative extension programs in Georgia, North Carolina, and South Carolina have participated actively in health programming using coalitions for wellness, lay-adviser community health, and agromedicine. One such program is the Community Health Advocacy Program in North Carolina. This program trains natural leaders from diverse socioeconomic backgrounds to disseminate information on health and health resources in their communities. Other programs include a demonstration site for a lay-adviser health program for agricultural workers and their families in western North Carolina and the dissemination of health promotion information on the Cherokee Indian Reservation in Appalachian North Carolina.

Under the auspices of CES community development programs, extension professionals at the local level in each of the three states regularly organize groups to address local issues. For example, in North Carolina, 150 extension-supported community clubs are active throughout the Appalachian counties. In addition, extension volunteer networks are in place to assist in the dissemination of programs—including the Family and Community Leadership Association (formerly Extension Homemakers)—with a national membership of 240,000. The extension service is implementing the Family and Community Leadership Program—funded by the Kellogg Foundation—that is operating in every state. This program has 2,500 graduates in Appalachian North Carolina alone who are serving on school boards and town councils and entering races for state offices (North Carolina Cooperative Extension Service 1993). The CES's Expanded Food and Nutrition Education Program (EFNEP) is an example of a successful effort for reaching families with limited resources and low reading skills. The Volunteer Information Provider Program and the Volunteer Adult Sitter Program are examples of successful programs that are reaching older residents. A diagram of the management team of the Southern Appalachia Leadership Initiative on Cancer is presented in Figure 1.

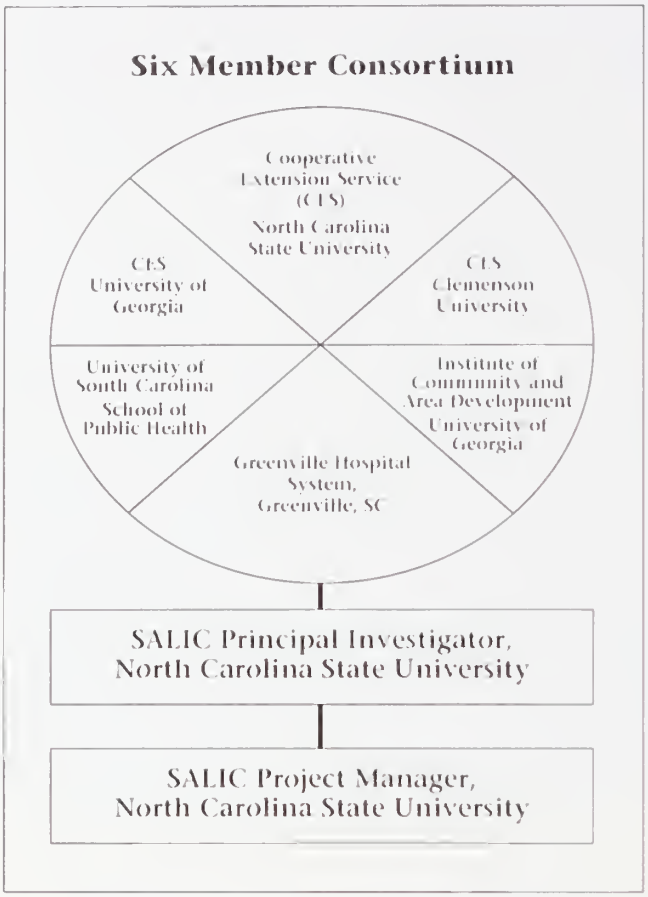
Populations to be Served

More than half the Appalachian counties in Georgia, North Carolina, and South Carolina targeted by SALIC are rural (Figure 1 in Introduction to Section III). Although this area is economically better off than Central Appalachia, poverty-level minimum-wage employment continues to be the norm for a substantial proportion of the population, particularly those living in the more rural areas.

Most of the 70 Appalachian counties located in Georgia, North Carolina, and South Carolina share a common history of isolation, poverty, low educational attainment, and high rates of disease and disability leading to early death. Incomes in the SALIC area tend to be considerably lower than the national average. Although per capita incomes for the three states served by SALIC were higher than the average per capita income for the total Appalachian region, they were lower than the U.S. per capita income of $18,746. Per capita income in North Carolina and South Carolina ranked 35th and 42nd, respectively, in the nation. In both states, the average hourly wage for workers in manufacturing was $2 less that the national average. The economy of North Carolina and South Carolina depends heavily on agriculture. Manufacturing accounts for the largest percentage of North Carolina's gross state product at 20.92 percent in 1991 (State Data Center 1991).

The median age of the counties' residents and the proportion of them age 65 years and older have changed over the decade as well. Although the populations of Georgia and South Carolina are younger than the national average, North Carolina and South Carolina are attracting increasingly more retirees. In 1990, 24 of North Carolina's 29 Appalachian counties had a population age 65 and over that exceeded the state's average of 12 percent for that age group (Appendix A). The North Carolina Department of Aging lists counties that have experienced a major influx of retirement communities. Among these, the mountain counties of Buncombe and Henderson

Figure 1. SALIC project organization


Six Member Consortium
Cooperative Extension Service (CES) North Carolina State University
CES University of Georgia
CES Clemenson University
University of South Carolina School of Public Health
Institute of Community and Area Development University of Georgia
Greenville Hospital System, Greenville, SC
SALIC Principal Investigator, North Carolina State University
SALIC Project Manager, North Carolina State University

have the largest number of such communities. The South Carolina Joint Legislative Committee on Aging currently lists 87 retirement communities in 23 counties across the state (South Carolina State Budget and Control Bureau 1992). The Blue Ridge foothills of Greenville County has the largest number, with nine retirement communities.

Further complicating efforts to decrease disease rates, including cancer, are the belief and value systems of many native Appalachians. These systems share the attributes of relatively isolated small-scale societies—belief in and reliance on fate, attachment to place and a sense of belonging, personalized interaction with others, strong kinship ties, emphasis on being as opposed to doing, strongly patterned conventional behaviors, belief in the traditional over the new, and strong religious tendencies even when not formalized.

The growth of information and transportation systems, the influx of foreign capital investment, and the development of metropolitan areas—such as Winston-Salem and Asheville, North Carolina; Atlanta, Georgia; and Greenville, South Carolina—have created a great deal of change in each of the three SALIC project states. The rural areas, the target of the SALIC project, are less transformed. Rural residents are still more likely than newly arrived residents or metropolitan residents to rely on kin or close neighbors for information and advice, to distrust impersonal messages and unknown messengers, and to hold tightly to beliefs and values, often in the face of contrary evidence.

However well tailored the content, cancer prevention and control messages must follow a time-honored delivery system, be delivered by trusted messengers, and consist of approaches deemed acceptable within Appalachian conventions and traditions. The need for tailored messages applies not only to the white mountaineer but also to the substantial Native American population (13,500 on the Cherokee Reservation), African-Americans, and the Hispanic migrant groups living either all or part of the year in the area served by SALIC.

Cancer prevention and control systems also must be prepared to work through the gatekeepers of the Appalachian family to reach the most vulnerable individuals. The gatekeepers are primarily the males or older women within the household. Although the women may have to be persuaded to adopt new attitudes or change behaviors, they generally must receive the support and permission of a husband, father, or other male before they take action. Few women, particularly older women who are most susceptible to cancer, have their own means of transportation in rural Appalachia. Influencing gatekeepers' attitudes is often the only way to effect change. Once males are convinced of the benefits of a new behavior, positive action is more likely.

Literacy rates and levels of educational

attainment also affect health. Georgia and North Carolina have some of the oldest and most distinguished colleges and universities in the nation. In addition, the Research Triangle Park area (Raleigh, Durham, Chapel Hill) of North Carolina claims to have the highest number of doctoral degrees per capita in the nation (Marketing Research Department 1988). However, most of the higher education institutions are predominantly in the metropolitan areas of these states. On the other hand, North Carolina and Georgia have some of the lowest percentages of high school graduates and spend fewer dollars per pupil than most states. South Carolina ranks 41st in the nation in spending per student and 34th in teachers' salaries. North Carolina has the highest rural nonfarming population in the nation, and the rural population of Georgia and South Carolina is also high (State Data Center 1991).

Common Characteristics of SALIC Communities

No typical community or target population exists within the geographic area served by SALIC. The more rural, isolated mountain areas feature small communities with several hundred households or fewer and no defined commercial centers. Social life may center on a church or community center. Appalachians raised in tradition and folklore are most likely to be found in these communities. Within a few miles of these communities, a resort or retirement community may be established for people who are drawn to the mountains from other states for recreation or retirement. A substantial African-American population resides in the lower elevations, where most of the industrial development has occurred.

Agricultural production in Appalachian Georgia, North Carolina, and South Carolina consists primarily of apples, Christmas trees, tobacco, dairy products, peaches, and poultry. Valleys in the region may have small- to medium-sized industries that employ a large portion of the native population from the area. These residents usually work for relatively low wages in the textile or furniture industries. Although SALIC focuses primarily on rural counties, two of the six Appalachian counties in South Carolina have large urban populations. These urban areas also depend on the textile industry.

Availability or accessibility of primary health care is a major barrier to cancer prevention and control in the SALIC region. Even where health care is available, many Appalachians are unable to pay for it. Lack of transportation is another major barrier to accessing health care.

Cultural barriers to cancer prevention and control include a fatalistic attitude about cancer. Many Appalachians are reluctant to submit themselves to clinical examination by a physician for reasons of modesty or propriety. Health care may not be a priority where the constant struggle for economic survival tends to obliterate symptoms of disease from consciousness until a health crisis occurs.

Lack of knowledge and understanding of cancer continues to be a barrier. Even well-meaning purveyors of information may increase the obstacles to cancer prevention and control if their messages are not presented in a way that is meaningful to Appalachians. The use of "cultural tales" to transmit information is under exploration as a method of imparting new knowledge to community members.

Appalachians often react to adversity with stoicism and resignation born of generations of dealing with a host of natural and human-made calamities. Economic deprivation and exploitation, dwindling food supplies, disease, floods, wildfires, and isolating blizzards have tested each generation. Studies have shown that the major fears of mountain children concern natural disasters, particularly flooding. With little else to depend on, Appalachians show a high level of self-sufficiency and willingness to put family

and neighbors ahead of themselves in time of need.

Incidence and Risk of Cancer

SALIC is concentrating its initial efforts on the early detection of breast and cervical cancer. In 1990 breast cancer incidence rates for white women were about equal to the U.S. rate in Georgia (108.4 per 100,000) and higher in North Carolina (122.6). For nonwhite women, the incidence rates were somewhat lower than the national rate (86.2 vs. 91.7). However, a comparison of the relationship between incidence and mortality in the two groups shows that nonwhite women with a diagnosis of breast cancer experienced considerably higher mortality (incidence/mortality ratios of 4.42 for whites vs. 3.01 for nonwhites) (Herman and Aldrich 1992).

An examination of data for 1984-1988 shows that in each SALIC state, mortality rates for breast and cervical cancer are substantially elevated in the African-American population. In North Carolina, whereas the 1984-1988 breast cancer mortality rate women was 26 per 100,000 for white women, it was 31.3 for black women. In Georgia, the mortality rate was 24.5 for white women and 28.6 for black women. Only South Carolina had similar rates: 25.4 for white and 25.6 for black women. The discrepancy was even greater—and consistent across states—for cervical cancer mortality. Although cervical cancer mortality rates for white women averaged 2.7 over the three states, the rate was 8.1 for black women—a threefold difference (National Cancer Institute 1991). In cervical cancer mortality rankings for 1984-1988, North Carolina, South Carolina, and Georgia black women were 8, 7, and 10, respectively; North Carolina and South Carolina white women were 15 and 17.

Although Appalachia's mountain populations are not predominantly minority, there are substantial numbers of African-Americans, Hispanics, and especially Native Americans. Appalachia includes a disproportionately high share of economically distressed communities that are at increased risk for cancer. The burden of cancer incidence is greatest among people with low incomes (Holleb 1989; Freeman 1989). Low-income people suffer a 20-percent higher rate of all cancers combined than do people with medium and high income levels, an 80-percent higher incidence of lung cancer, a 41-percent higher incidence of rectal cancer, and a 400-percent higher rate of cervical cancer. Furthermore, people with low incomes have lower 5-year cancer survival rates than economically advantaged people. Reasons for this socioeconomic disparity in cancer incidence and mortality include different lifestyle choices, lack of health insurance and access to preventive health services, and lack of perceived benefits to prevention and early detection (see Chapter 7, this volume).

Differences between cancer incidence and mortality rates raise concerns about obstacles to screening (Liff et al. 1991; Monroe et al., in press). In Georgia and North Carolina, significant issues associated with stage at diagnosis have become apparent through recent analyses by race groups and urban and rural populations. Rural women in Georgia and North Carolina are more likely to have later stages at diagnosis for breast cancer among both whites and African-Americans (Liff et al. 1991; Monroe et al., in press). Among African-Americans in North Carolina, rural men are more likely to have later stages at diagnosis for prostate cancer (Monroe et al., in press).

The cancer problem has evolved into two separate issues: contracting cancer and dying from cancer. Today, more than half the persons diagnosed with cancer will not die from the disease (Boring et al. 1992). Of those dying from cancer, one-third could have been saved through early detection. For example, the government reports that about 50 percent of Georgians with cancer could be cured if detected early.

Risk factors for contracting cancer have been the subject of research for years; in recent times, attention also is turning to disease prevention and control efforts or avoiding dying from cancer. For the overwhelming majority of cancers, beliefs, attitudes, and practices are the targets for intervention. The aspects of an individual's beliefs, attitudes, and practices in need of modification vary by the objective (risk avoidance versus early detection). In the southeastern United States, these issues of incidence versus mortality only recently have begun to be examined.

Mobilizing Leaders

SALIC's organizational structure comprises three major tiers of linkages, which bring together individuals and organizations that can supply resources and expertise from the national and state levels as well as those who have knowledge of the needs, values, and practices in local communities. These tiers, depicted in the SALIC organization chart in Figure 2, are state, county, and community levels.

First Tier—State Level

A three-state consortium to reduce cancer morbidity and mortality in the Appalachian counties has been formed by the Cooperative Extension Service programs at University of Georgia, North Carolina State University, Clemson University, the Institute of Community and Area Development at the University of Georgia, the School of Public Health at the University of South Carolina, and the Greenville Hospital System in Greenville, South Carolina. The principal investigators from each of the six SALIC consortium institutions serve on the SALIC management team (Figure 1). The SALIC project manager also is a member of this overall management team. The Tri-State SALIC Coalition, shown in Figure 2, functions in an advisory capacity to the SALIC management team. Members of the coalition include individuals and organizations with extensive experience in Appalachia, community development, cancer control, cancer communication and education, information dissemination, and volunteer systems. Organizations represented on this coalition are the Regional Cancer Information Service, Duke University Cancer Center; state health department epidemiology and cancer control programs, including comprehensive breast and cervical cancer control programs and the American Stop Smoking Intervention Study for Cancer Prevention (ASSIST), state cancer registries, academic departments of health promotion and education, epidemiology and biostatistics, sociology, and education; the American Cancer Society; community resource development and evaluation units of the Cooperative Extension Service (CES); and CES-sponsored homemakers' clubs.

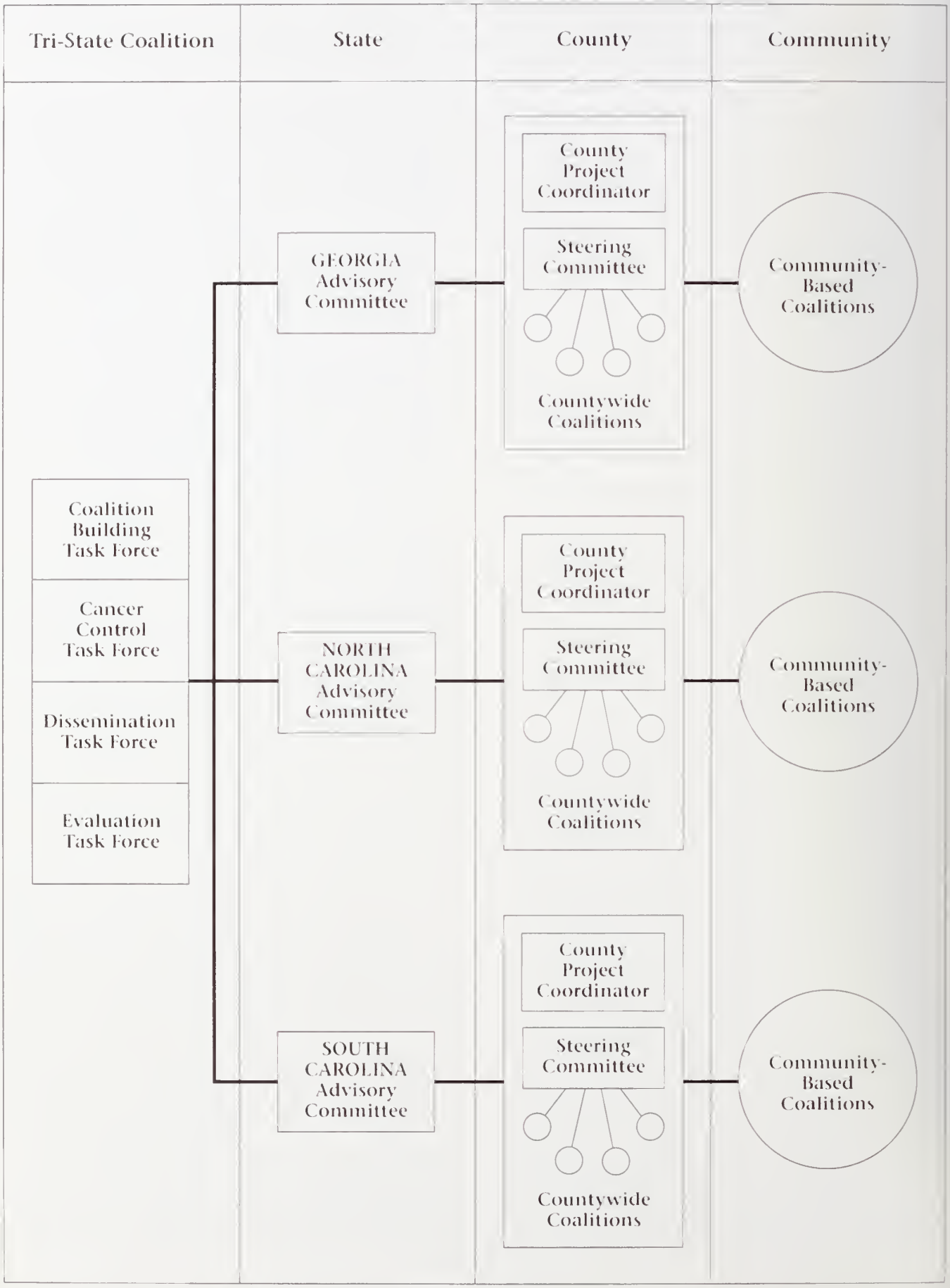
This multistate coalition has four task forces—coalition-building, cancer control, dissemination, and evaluation—that assist in providing direction and formulating content for their specific areas of expertise. The SALIC Tri-State Coalition has invited other relevant groups, including area health education centers and Community Cancer Oncology Programs, to join in this effort.

Each state also has a state advisory committee, largely derived from the Tri-State Coalition membership. Advisory committees support state project coordinators by helping planners decide on state-specific strategies and communications channels, assessing the cancer-related needs of Appalachian communities in their states, and identifying educational materials for special populations.

Second Tier—County Level

Each state served by SALIC has a project coordinator who is employed by the state extension service and located at an extension center within that state's multicounty Appalachian site. Project coordinators possess pertinent experience in community health

Figure 1. SALIC parallels of linkages



issues. These coordinators are assisted by CES agents.

Where county populations are too small to support viable county coalitions, multicounty coalitions will be formed to guide program planning at the county level. Representatives of these coalitions will work with the project coordinator to assess county needs and support community coalitions. The countywide coalitions will include a racial, gender, and socioeconomic cross-section representative of Appalachian community residents as well as professionals from county agencies such as health departments and social services. Countywide coalition members are being identified through a systematic series of interviews conducted by project coordinators. Some responsibilities of countywide coalitions are to assist in identifying the cancer prevention and control needs of Appalachian communities, identify participants and help organize focus groups in five to seven Appalachian communities, and advise SALIC management staff on appropriate and effective programming strategies, channels of communication, and educational materials.

Third Tier—Community Level

A rural community is defined here as an incorporated or unincorporated town or other geographically contained rural area identified as a community by its residents. Community-based coalitions will consist of members of local resident groups and organizations, including representatives from churches, women's groups, chambers of commerce, local governments, hospitals, community action agencies, and private businesses. Coalition members will be selected for their demonstrated commitment to community health and well-being as well as for their interest in cancer prevention and control. Coalition members, in turn, will help identify volunteers who will be drawn from the coalition membership or from other respected and concerned residents to whom neighbors turn for advice.

Building Blocks of Coalitions

The central research question of SALIC is to what extent community cancer prevention and control coalitions are effective in increasing awareness of cancer and in changing attitudes and behavior associated with cancer risk and survival. It is envisioned that, with the technical assistance and support of SALIC staff, the residents of rural Southern Appalachian communities will be empowered to act on their own behalf to decrease cancer incidence and mortality.

SALIC has several specific goals based on those of the overall ALIC program.

- SALIC will mobilize community lay and professional leaders to develop and support cancer prevention and control coalitions and outreach activities countywide in the study counties.
- These countywide coalitions will work with community residents, including representatives from small rural communities within the county, and will create a network of community-based cancer prevention and control coalitions.
- A major function of the community-based coalitions will be to develop, coordinate, and nurture a volunteer cancer prevention and control system to supplement the efforts of paid SALIC extension agents and community leaders.
- With technical assistance from SALIC staff, these community-based cancer coalitions will develop, disseminate, and support effective cancer prevention and control intervention programs and strategies for local communities and will work with the countywide coalitions to resolve problems of availability, accessibility, and affordability of cancer diagnosis and subsequent treatment.
- Evaluation protocols will be developed to help the community-based and countywide coalitions measure their progress and effectiveness in achieving their objectives. An over-

all evaluation of the project will be instituted to determine the effectiveness of cancer prevention and control coalitions in changing knowledge levels, attitudes, and behaviors about cancer.

► SALIC will attempt to stimulate cancer prevention and control data collection and research either as part of the project or in collaboration with cancer researchers in agencies and universities throughout the three-state area.

Building a Network of Coalitions

Most rural communities have few outside resources and many needs. They must form groups and coalitions to find workable solutions to their problems. Although the interest of communities may be high, individuals often do not know how to mobilize groups into coalitions that engender full community participation and address critical issues effectively. Consequently, the role of the Institute of Community and Area Development at the University of Georgia in the SALIC project is to develop a coalition-building training program and to teach a series of trainings on coalition building and group process skills for SALIC coordinators and CES agents. This training series will enable coordinators and agents to develop tools and practice skills that are necessary for forming and maintaining coalitions.

The underlying assumptions of this training series are as follows:

► Members of a coalition need to represent diverse sections of the community. The real experts are those who deal with the problems in the community; therefore, they must participate in finding solutions.

►When members of a coalition feel that they are part of a group, they often relinquish some of their self-interest.

► When individual members contribute input to the group decision, a stronger commitment to action results.

► When group commitment and ownership develop, outreach programs are more likely to be implemented.

In addition to the local CES agent, at least one individual from each of the study counties in the coalition training will be involved by the project coordinators. The initial coalition-building training will address recruitment and creation of a coalition, group process skills, coalition strategies, and ways to sustain a coalition. By the end of the program, local teams will have developed the tools and practiced the skills needed to form coalitions and to encourage local participation in the development of cancer outreach programs. The teams also will have outlined a plan of action to build coalitions in their communities. After returning from the coalition training sessions, these core teams will initiate the county cancer prevention and control coalitions. Community-based coalitions will follow.

Developing and Disseminating Intervention Programs and Strategies

SALIC will focus on the following targets for intervention through local organizations:

► Primary prevention of lung and skin cancers (melanomas);

► Secondary prevention of cancers of the breast, cervix, and skin; and

► Dietary changes, such as lowering fat consumption and increasing consumption of specific fruits and vegetables.

A central SALIC strategy will be to identify and assist local organizations in adapting and using National Cancer Institute (NCI) messages and materials. Programs will be adopted, modified, or developed for the types of cancer identified for targeting. For example, the Cancer Information Service (CIS) will train SALIC coalition members to present breast cancer early detection programs to women in their communities. Emphasis will be placed on reaching rural women in isolated commu-

nities. CIS will provide speaker's kits to training participants and make CIS education programs available. CIS will continue to provide technical assistance on an ongoing basis. All materials will be reviewed for literacy level and modified if necessary to tailor specific messages to the target audience.

To ensure competency in relaying NCI messages to communities, SALIC staff and interested coalition members will receive extensive training on the biology and epidemiology of cancer as well as cancer prevention and control. In addition to the training provided by CIS, a graduate-level, 3-hour course, "A Multidisciplinary Approach to Cancer," will be offered. This will be coordinated by the SALIC principal investigator.

Because the relationship between diet and cancer is of major interest and cuts across a number of cancers and other health concerns, intervention methods for dietary change will involve mass media, including radio, newspapers, newsletters, bulletin boards, posters, and printed materials; workshops; and demonstrations. SALIC will involve the local grocery stores in a point-of-purchase effort that includes shelf labeling, displays, handouts, and in-store taste-testing demonstrations.

Project Evaluation

SALIC is gathering statistics on cancer and cancer-related health issues for evaluation of the project. For example, SALIC has formed alliances to share data with cancer registries in Georgia and North Carolina. In South Carolina, where no data currently exist regarding the incidence of cancer, a tumor registry is being established for the Appalachian area of that state through SALIC. South Carolina SALIC coalition members also have joined a task force to establish a statewide cancer registry.

Although data on the prevalence of certain risk factors and screening behavior are available from the Behavioral Risk Factor Surveillance System (BRFSS), these data cannot be linked to occurrence of disease. Nevertheless, because they may be useful, SALIC has made agreements in Georgia and South Carolina to gather supplemental BRFSS data for the evaluation of the project.

SALIC also will collect demographic and other data on clusters of counties in the project area. These county groupings will be characterized according to the availability and type of health care, levels of access to highways and roads, degree of industrialization, levels of education and income, and family size. Data on health status and use of health services will be obtained from health departments, state data centers, and hospital and clinic sites.

SALIC is developing a computerized geographic information system to analyze and map these county data. This system, coupled with standard statistical packages, will permit the analysis and display of spatial patterns against such things as roads and telephone service. SALIC will generate a series of maps that depict the characteristics of county groupings and provide baseline information about selected counties. Similar maps will be drawn throughout the study to help determine the effects of the community intervention.

Data on the knowledge, attitudes, and behavior in the SALIC area will be collected by three methods:

- Supplemented BRFSS data;
- Pretesting and posttesting of focus groups in counties participating in the project's study; and
- Telephone knowledge, attitude, and behavior surveys conducted in a sample of participating and nonparticipating counties.

SALIC also will develop mechanisms for collecting data on referrals to regional cancer treatment centers.

Among ALIC projects, SALIC has the most extensive research design. SALIC will conduct a randomized, controlled community trial of community mobilization efforts and cancer

prevention and control intervention strategies. The project has created clusters of three to four counties within each state in the project area based on demographics, county size, transportation, trading patterns, and prior regional groupings. One cluster per state has been randomly selected as a study site. An additional cluster, closely matching the first, will serve as a comparison site. Any measurement activity that can be administered to both coalition and comparison counties will be administered alike. The only difference between the two groups of counties will be in receiving or not receiving assistance in forming coalitions and other kinds of continuing education and administrative assistance. A demographic study and other sources of information will be used to ensure that high-risk populations will be represented appropriately when samples are drawn for population studies.

Process Evaluation

SALIC's process evaluation will determine the extent and quality of the community coalitions that have been formed as well as the community education efforts that they implement. Ongoing monitoring of project activities will provide feedback to SALIC staff for improving and redirecting coalition-building and community education efforts. Results of the process evaluation will provide information essential not only for adapting SALIC strategies to other populations but also for increasing understanding of the dynamics of coalition building for the institutionalization of community education in rural communities.

Process evaluation will include a description of the program development process to identify:

- Obstacles or constraints affecting the timely development of the cancer prevention and control community coalitions and effective educational modules on coalition building and the understanding of cancer; and
- Effective methods of facilitating or operating cancer prevention and control community coalitions and disseminating targeted messages to culturally diverse audiences.

Institutional support, educational manuals and other materials, involvement of SALIC personnel in coalition building and training, networking, cancer surveillance, and evolving cancer prevention and control programs will be described.

Outcome Evaluation

SALIC's outcome evaluation will determine the overall success of the project's educational strategies for improving cancer prevention and control in the targeted counties. Outcome measures will include:

- The number of presentations, persons and organizations participating in the cancer prevention and control community coalitions, and educational experiences and volunteer training conducted;
- Measurements of changes in knowledge, attitudes, and behavior related to cancer prevention and control among community coalition leaders and members, volunteers, and community members; and
- Changes in the incidence and mortality related to specific targeted cancers. Although these changes will not be measurable over the 5 years of the SALIC project, baseline data will be collected and subsequent surveillance will be instituted to provide historical data to future cancer prevention and control activities institutionalized within CES.

SALIC will use focus groups to assess cancer-related knowledge, attitudes, and behavior prior to the development of educational methods and materials. The acceptability and impact of the educational experiences will be determined through pretests and posttests. These instruments will provide baseline data for evaluating SALIC effectiveness. Because not all counties will have participated in the project, SALIC will conduct telephone surveys of knowledge, attitudes, and behavior in a sam-

ple of the nonparticipating communities outside the study areas to determine the effect of exposure to the SALIC experience. Data from the survey will be compared with supplemented BRFSS data. To help clarify findings, SALIC will collect additional demographic and other data regarding project participants and survey respondents.

If the proposed coalitions are effective, several differences between intervention and control counties are expected to emerge, including:

- Greater increases in telephone contacts to and referrals from CIS for SALIC intervention counties versus SALIC control counties;
- Greater reductions in high-risk lifestyle-related behaviors and increases in self-reported screening behaviors (e.g., Pap test in previous year, mammogram in previous 2 years, regular breast self-examination, regular physician visits) in intervention counties versus control counties determined by BRFSS responses;
- Greater increases in the incidence of breast cancer and melanoma in intervention counties versus control counties as a result of intensified screening;
- Greater increases in proportion of early-stage cancers diagnosed in intervention counties versus control counties; and
- Greater increased referrals to cancer treatment centers from intervention counties versus control counties.

Initial Planning Issues

The first challenge faced by SALIC was building a management team. The team comprises the six-member consortium involving faculty members from four state universities and the Greenville Hospital System in South Carolina (see Figure 1).

In collaboration with the Tri-State Coalition, the SALIC management team also has coordinated the work of the tristate task forces. In a participatory and collective mode, SALIC's multistate coalition, management team, and staff have striven to define clearly their respective roles in meeting the goals of the study, to diagram the anticipated sequence of project activities, and to integrate the work of the task forces in a timely manner so as to satisfy the project objectives for the next 4-1/2 years.

Members of the evaluation task force, the management team, and consultants also have focused on identifying a formative evaluation model to measure the progress of the project as it is implemented. Research methods and models also are being selected to determine the effect of SALIC on changes in knowledge, attitudes, and behavior among individuals living in counties participating in the program, compared with those in nonparticipating counties.

Another issue faced during the SALIC planning phase is defining and distinguishing between countywide and community-based coalitions. SALIC needs to define clearly the respective organizational structures and roles for both types of coalition. The countywide coalitions will comprise representatives from agencies, institutions, county government, businesses, civic organizations, and others largely identified by survey or by their occupation or position. To this group will be added representatives from the rural communities. Community-based coalitions will include community leaders and interested residents, whatever their position in the community.

Depending on the situation in the individual state, coalitions may begin with either of these two separate but interlinked types. In Georgia, for example, CES agents traditionally have worked directly with small communities and have been active in the formation of local coalitions involving local community leaders. Therefore, community-based coalitions may be first to form. However, countywide coalitions may form first in large communities such as Anderson, South Carolina, where most of the coalition building has centered on countywide coalitions targeting a larger audience and greater geographic scope.

Because SALIC is a randomized, controlled community trial, its intervention activities will be limited to the randomly-selected geographic sites rather than targeting the entire Appalachian population of the three states. Consequently, some time may pass before any benefits derived from SALIC are available to the total population of the area.

SALIC is not designed to address the broader environmental factors associated with cancer etiology, such as the possible effects of pesticide runoff on water quality and industrial contamination of land, which some residents believe may contribute to the excessive rates of certain types of cancer in the area. Achieving SALIC's aims, despite overriding concern with these environmental issues in many communities, will be a continuing challenge to the project. SALIC management and staff will need to understand and be sensitive to these concerns as the project is implemented.

SALIC recognizes that the project has many lessons to learn, including:

- Better understanding of Appalachia's history, culture, economy, and cancer problem;
- Identifying similarities and dissimilarities among SALIC communities;
- Designing and delivering tailored messages to disseminate information and new knowledge to rural communities; and
- Using focus groups to collect information about communities and their attitudes and behaviors concerning cancer.

This information will serve as a guide in the implementation phase beginning with the second year.

During the first 6 months of SALIC's planning year, individuals involved in the original

Project Characteristics of the Southern Appalachia Leadership Initiative on Cancer

1. The Southern Appalachia Leadership Initiative on Cancer (SALIC) will be conducted by the North Carolina Cooperative Extension Service at North Carolina State University in association with Cooperative Extension Service programs at the University of Georgia and Clemson University. The Greenville Hospital System, the School of Public Health at the University of South Carolina, and the Institute of Community and Area Development also will participate in SALIC.

2. SALIC will target rural areas in North Carolina, South Carolina, and Georgia in which poverty-level, minimum-wage employment is the norm for a substantial part of the population.

3. SALIC will address barriers to cancer prevention and control such as lack of availability or accessibility of primary health care, transportation, ability to pay for services, and lack of knowledge and understanding of cancer.

4. SALIC will form linkages among tiers of coalitions at the state, county, and community levels, bringing together individuals and organizations that can supply resources and expertise from national, state, and local levels.

5. SALIC will have a three-state consortium to guide the program at the state level (first tier) and serve as SALIC's management team.

6. SALIC will have single-county and multicounty coalitions to guide program planning at the county level (second tier).

7. SALIC will help second-tier coalition members assess county needs and support community coalitions.

8. SALIC's community-based coalitions (third tier) will consist of members of local resident groups and organizations, including representatives from churches, women's groups, chambers of commerce, local governments, hospitals, community action agencies, and private businesses.

9. SALIC will work to enable the residents of rural southern Appalachian communities to act on their own to decrease cancer incidence and mortality.

10. SALIC will form alliances to share data with cancer registries to gather statistics on cancer and cancer-related health issues for evaluation of the project.

11. SALIC will conduct a randomized, controlled community trial of community mobilization efforts and cancer prevention and control intervention strategies.

12. SALIC will conduct a process evaluation to determine the extent and quality of the community coalitions that are formed and the education efforts that they implement. Results will be used to improve and redirect coalition building and community education efforts.

13. SALIC will conduct an outcome evaluation to determine the overall success of the project's intervention strategies for improving cancer prevention and control in the targeted counties.

formulation of this project have retained their interest and enthusiasm. Participants who are part of the consortium receiving financial support for implementing components of the project as well as those engaged in SALIC as an addendum to their major responsibilities continue to contribute beyond expectation.

Counties and communities have indicated an eagerness to participate in coalition building. One lesson well learned is that project staff members need to offer opportunities for involvement soon after introducing SALIC to county and community leaders. These individuals are eager to learn when they can begin participating and how they can contribute immediately. SALIC has sought to include these leaders in the project's planning process. They are helping to identify other local leaders, to recruit focus group participants, and to form the nucleus of the countywide coalitions.

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CONCLUSION

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ALIC has made coalition building a central strategy of its program. Consequently, each of the four ALIC projects has assessed its potential to mobilize state and local leaders in Appalachia and to build coalitions among established Appalachian health-related organizations, health care providers, colleges and universities with significant Appalachian student enrollment, the business community, and other relevant community-based organizations. ALIC projects have a strategy of establishing coalitions in specific places with the leaders found there. Obviously, the severity of the incidence and mortality of various cancers and the capacity and availability of leaders will shape priority areas and programs for each ALIC project. Eventually, however, each ALIC project intends to blanket its portion of Appalachia with coalition activity.

The institutional context of each project's lead organizations has a profound influence on each ALIC project. The two extension-related projects have a network with agents and programs already in place in each county in the region. These projects will introduce a specific agenda of tasks and activities related to cancer prevention and control into existing extension programs.

The two cancer center projects—North Central ALIC and Central Highlands ALIC—begin with their extensive cancer prevention and control resources and propose to work with other existing networks to extend those resources in a new way. Both projects have worked in collaboration with other cancer centers and other programs to institute information programs, registries, and outreach services for screening and early detection.

Each ALIC project may be distinguished by four dimensions:

- The nature of the award institution;
- The profile of the target population;
- The epidemiology of cancer and cancer risks within the target area; and
- The resources available for programs and types of current program activities.

The ALIC program provides each of its projects with a common set of goals and objectives. These are to:

- Reduce cancer rates, improve cancer survival, and prevent future cancer rate increases;
- Increase access to quality cancer control services and referral;
- Create a network of cancer control community coalitions;
- Implement cancer control intervention programs and activities;
- Mobilize community lay and professional leaders;
- Stimulate cancer control data collection and research efforts; and
- Evaluate the initiative.

Prospects

Fundamentally, a community-based coalition for health intervention, such as those in ALIC, brings together two current emphases in public policy and programs. First, within health care, these coalitions represent a realization that much of the illness and many premature deaths are preventable. Illnesses, such as some types of cancer, are associated with some behaviors, such as smoking, that can be changed. The prevention of disease is part of the effort to promote health and not "cure" illness.

The second emphasis within public policy and programs that community-based coalitions, such as ALIC projects, represent is increased participation of people affected by a problem and of people with direct responsibility for implementing programs. We have a lexicon of terms to express our hope and confidence in these forms of participation. They include "grassroots" and "empowerment" (Couto 1990).

Over the course of this monograph, we have covered the variety of community-based coalitions, the variety of outcomes to which they are related, and the depth of hope people in different areas invest in them. Some observers see them as a powerful force for sweeping change that can cause conflict. On the other hand, other observers advocate community-based coalitions as a less conflictual mechanism of more effective implementation of existing resources, of dissemination of existing information, of outreach to and recruitment of those not currently reached by services, and of support for those who attempt innovation and improvement of current practices and conditions.

Principles of Practice

Perhaps the first and most important principle of effective coalition practice is to reduce major factions among members. Factions divide groups rather than adding to group cohesion and multiplying group effectiveness. Boundary pullers and pushers, despite their differences, share common ground. Both groups intend to move in similar directions, even if at different speeds. They may even have common experiences in promoting change in their respective settings. Professionals within an institution, for example, often find themselves pushing the boundaries of their system by pulling at the boundaries of their particular institutions. Patients and activists, on the other hand, pull at others but may find themselves pushing the boundaries of their own organizations just as frequently. Major divisions might be lessened in coalitions by the frank admission of differences among members and the recognition of the willingness to work on common ground for change that is explicit in the willingness to join and participate in a coalition.

Similarly, another first principle is to embrace diverse perspectives. For some coalition members, the ALIC project will appear as a top-down approach. The ALIC project staff will need to work hard to establish credibility with community grassroots organizations. For others, the ALIC projects will appear as a bottom-up approach because ALIC uses organizations outside NCI in coalition efforts for cancer prevention and control.

Successful coalitions will accommodate and speak to both perspectives. This begins with a broad recruitment strategy. It continues with the willingness of coalition members to learn from one another. That willingness is obviously related to coalition members' ability to discuss and communicate with each other. Coalitions expand the variety of its members in direct proportion to the agreement among its members on what its members do not know and their willingness to learn about the condition they want to address and the methods to do so. Conversely, coalitions with members who have certainty about what is known and a primary interest to teach others are more likely to contract to fit the base of

knowledge on which the coalition rests.

Successful coalitions also are more likely to plan interventions across a breadth of interrelated problems. They do so in a manner accountable to the families and communities they serve, by collaborative planning.

The Community Intervention Trial for Smoking Cessation (COMMIT) of NCI provides the following principles of effective action for successful coalitions;

- ▶ Provide enough time for coalition members to recruit sufficient members, assimilate information, and develop internal cohesion.
- ▶ Include a broad array of members with experience in civic projects that cross the boundaries of issues and incorporate many different local organizations.
- ▶ Clarify role definition of community groups and institutional sponsors early and negotiate and renegotiate it as time goes on. Likewise, clarify goals and program elements to establish trust and a sense of ownership among community participants.
- ▶ Recognize and reward the incentive of community representatives to participate in coalitions that is premised on their belief that they know more than institutional sponsors about getting results locally.
- ▶ Expect that local initiative and creativity may foster other agendas for action while pursuing initial program goals. Likewise, expect that coalition goals will vary from place to place and over time.
- ▶ Train coalition members in tasks such as media advocacy and organization management as well as in conflict resolution and influencing health care providers.

Other lessons acquired within NCI emphasize the need for clear, open, and honest communication among the multilevel infrastructure of the project, assisting individual coalitions to recognize opportunities and problems. Dissemination of lessons, both good and bad, fosters the replication of success and hinders the repetition of mistakes. This communication also reduces the risk of adversarial relations over control or lack of focus between institutional sponsors and coalition members. It also can emphasize uncovering local resources rather than replacing them.

These lessons express some of the valuable experience of COMMIT and other coalition efforts of NCI; they summarize central points of other coalition and organizing efforts in general, in Appalachia, and on breast cancer. This intersection of common points of varying views illustrates the hope expressed by ALIC projects and other community-based health interventions to combine varying perspectives into a focused effort to address needs of a group or community. That such an intersection is possible enhances the prospect of ALIC projects, and those like it, to deal successfully with the problems before them. Insofar as the lessons at this intersection of experience are accurate, projects such as ALIC stand to benefit. Insofar as ALIC projects will bring new experience to that intersection of coalition lessons, they will instruct and benefit us all.

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Appendices

Appendix A

Selected Characteristics of Appalachia and Appalachian Counties

Summary Level	1990 Census Population	% Change Pop. 1970-1980	% Change Pop. 1980-1990	1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
Total United States	248,799,500	11.5	9.8	12.6	9,526	18,746
Total Appalachia	20,701,400	11.1	1.6	14.3	7,790	15,331
Northern	9,917,800	4.1	-3.1	15.7	8,343	15,722
Central	2,015,200	21.4	-4.7	13.3	6,438	12,315
Southern	8,768,400	18.8	9.4	12.9	7,441	15,582
AL Total	4,040,500	13.1	3.8	12.9	7,482	15,018
AL App. Part	2,529,600	13.8	4.1	13.0	7,696	15,636
AL Bibb	16,600	13.8	5.7	12.7	6,037	12,114
AL Blount	39,200	35.7	7.4	13.1	5,245	13,135
AL Calhoun	116,000	16.3	-3.2	12.4	7,122	13,776
AL Chambers	36,900	7.7	-5.9	16.9	6,678	12,968
AL Cherokee	19,500	20.5	3.7	14.8	5,642	12,642
AL Chilton	32,500	21.4	6.2	13.9	6,043	12,043
AL Clay	13,300	8.7	-2.9	16.8	6,061	12,948
AL Cleburne	12,700	14.5	0.8	13.4	5,509	12,287
AL Colbert	51,700	10.1	-5.1	14.7	7,689	13,380
AL Coosa	11,100	7.5	-2.6	14.4	5,886	10,664
AL Cullman	67,600	17.6	9.7	14.5	6,638	13,794
AL DeKalb	54,700	28.2	1.9	14.6	5,733	14,374
AL Elmore	49,200	29.6	13.4	11.7	7,060	14,870
AL Etowah	99,800	9.6	-3.2	15.9	7,425	13,394
AL Fayette	18,000	16.0	-4.3	16.3	6,648	12,352
AL Franklin	27,800	18.8	-2.1	15.5	6,692	13,736
AL Jackson	47,800	31.1	-7.0	12.6	7,046	12,767
AL Jefferson	651,500	4.1	-2.9	14.0	9,375	18,624
AL Lamar	15,700	14.6	-4.8	15.7	6,786	12,636
AL Lauderdale	79,700	18.4	-1.0	14.3	7,920	14,403
AL Lawrence	31,500	11.0	4.3	11.9	5,562	11,763
AL Limestone	54,100	10.3	17.6	11.3	6,488	14,617
AL Madison	238,900	5.6	21.3	9.0	8,896	18,990
AL Marion	29,800	26.6	-0.7	15.2	6,008	11,001
AL Marshall	70,800	21.0	7.9	14.1	7,224	15,204
AL Morgan	100,000	16.7	10.9	11.7	7,521	16,458
AL Pickens	20,700	5.9	-3.7	16.4	6,044	11,418
AL Randolph	19,900	9.8	-1.0	16.5	5,643	12,069

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate† 1984-1988	1990 Pop. per Patient-Care Doctor	1988 USDA‡, ♦ Rural/ Urban Code	ARC§, ♦ 1988 Distressed Counties
Total United States	5.5	12.8	75.2	10.4	516.4		
Total Appalachia	6.2	14.8	68.4	10.4	680.8		
Northern	6.4	13.6	73.3	9.6	626.2		
Central	7.9	25.3	53.3	10.8	1,046.3		
Southern	5.7	13.8	66.1	11.2	693.5		
AL Total	6.8	17.9	66.9	12.6	673.5		
AL App. Part	6.5	15.5	67.1	12.2	625.5		
AL Bibb	8.6	21.2	51.8	13.2	1,844.4	6	1
AL Blount	7.4	15.3	60.5	7.5	3,266.7	2	2
AL Calhoun	7.0	15.7	67.4	12.8	899.2	3	3
AL Chambers	7.3	18.8	54.3	18.3	1,366.7	5	3
AL Cherokee	10.4	17.6	53.5	13.9	2,785.7	8	1
AL Chilton	8.8	17.1	56.6	14.1	2,954.5	6	1
AL Clay	6.2	17.4	53.8	27.5	2,660.0	9	1
AL Cleburne	7.2	15.3	49.8	9.9	3,175.0	6	2
AL Colbert	7.9	14.6	65.2	11.4	907.0	3	3
AL Coosa	6.2	18.2	53.9	12.8	5,550.0	8	3
AL Cullman	7.1	15.3	58.8	13.5	1,229.1	6	3
AL DeKalb	7.0	17.4	53.0	11.8	2,025.9	6	2
AL Elmore	6.0	14.5	66.5	11.7	2,236.4	2	3
AL Etowah	10.7	16.5	64.1	12.2	702.8	3	3
AL Fayette	9.4	20.3	56.6	12.2	1,800.0	6	3
AL Franklin	10.5	20.7	55.1	11.5	1,463.2	6	3
AL Jackson	9.8	16.6	58.1	8.5	1,770.4	4	2
AL Jefferson	5.1	16.0	73.8	13.7	288.0	2	3
AL Lamar	7.5	18.0	52.9	10.2	3,140.0	7	3
AL Lauderdale	6.6	14.9	67.9	10.4	705.3	3	3
AL Lawrence	9.7	19.8	55.6	12.0	2,423.1	6	1
AL Limestone	5.9	14.0	63.1	9.8	2,352.2	6	3
AL Madison	4.7	10.9	80.2	9.8	620.5	3	3
AL Marion	12.3	19.1	50.0	10.0	1,655.6	7	2
AL Marshall	7.7	17.2	61.5	11.2	1,609.1	4	3
AL Morgan	6.6	12.0	69.4	9.4	833.3	4	3
AL Pickens	10.3	28.9	56.2	16.3	2,070.0	6	1
AL Randolph	8.3	18.9	50.3	12.9	2,487.5	7	1

continued

Selected Characteristics of Appalachia and Appalachian Counties (continued)

Summary Level	1990 Census Population	% Change Pop. 1970-1980	% Change Pop. 1980-1990	1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
AL Shelby	99,400	74.9	49.9	7.6	6,892	15,935
AL St. Clair	50,000	47.7	21.4	11.6	6,050	13,056
AL Talladega	74,100	13.2	0.4	12.9	6,291	12,212
AL Tallapoosa	38,800	14.5	0.3	16.1	6,641	14,235
AL Tuscaloosa	150,500	18.5	9.5	11.3	7,032	15,113
AL Walker	67,700	22.2	-1.5	14.4	7,855	14,556
AL Winston	22,100	32.5	0.5	14.1	6,274	12,023
GA Total	6,477,700	19.1	18.6	10.1	8,087	17,114
GA App. Part	1,508,000	35.8	36.6	9.7	7,127	16,420
GA Banks	10,300	26.1	18.4	11.5	5,225	13,906
GA Barrow	29,700	27.4	38.8	10.9	7,264	14,322
GA Bartow	55,900	24.8	37.0	10.0	7,285	14,007
GA Carroll	71,400	24.3	26.8	10.2	6,975	14,463
GA Catoosa	42,500	30.7	14.9	10.9	5,548	12,860
GA Chattooga	22,200	6.3	1.4	14.9	6,102	11,867
GA Cherokee	90,200	66.8	74.5	7.0	5,935	18,035
GA Dade	13,100	24.2	6.5	10.9	5,556	10,728
GA Dawson	9,400	33.3	95.8	8.9	6,962	13,313
GA Douglas	71,100	90.2	30.2	7.0	7,418	17,217
GA Fannin	16,000	10.5	8.8	17.9	5,671	12,313
GA Floyd	81,300	8.3	1.9	14.6	8,079	16,062
GA Forsyth	44,100	64.7	57.5	8.9	6,494	20,455
GA Franklin	16,700	18.8	9.9	15.5	6,197	14,760
GA Gilmer	13,400	24.7	20.7	13.6	6,401	15,236
GA Gordon	35,100	27.5	16.6	10.7	6,888	14,885
GA Gwinnett	352,900	130.8	111.4	4.8	8,088	19,861
GA Habersham	27,600	20.8	10.4	13.2	6,407	15,125
GA Hall	95,400	27.5	26.2	10.8	8,276	16,943
GA Haralson	22,000	15.7	19.6	13.3	7,216	13,336
GA Heard	8,600	20.4	32.3	12.0	6,910	11,132
GA Jackson	30,000	19.9	18.6	12.0	6,561	15,328
GA Lumpkin	14,600	24.1	35.2	10.1	5,427	14,351
GA Madison	21,100	31.1	19.2	11.0	5,970	13,057
GA Murray	26,100	51.5	32.5	8.2	6,413	12,399
GA Paulding	41,600	49.1	59.4	7.3	6,321	13,613
GA Pickens	14,400	21.9	23.1	13.5	6,672	15,770
GA Polk	33,800	9.5	4.3	14.2	6,858	12,767
GA Rabun	11,600	26.5	10.5	18.2	5,538	12,657

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate † 1984-1988	1990 Pop. per Patient-Care Doctor	1988 USDA‡, ♦ Rural/ Urban Code	ARC §, ♦ 1988 Distressed Counties
AL Shelby	3.9	9.2	78.2	9.6	1,875.5	2	3
AL St. Clair	6.0	14.8	61.0	10.4	2,777.8	2	3
AL Talladega	9.6	20.2	60.7	11.1	1,576.6	4	1
AL Tallapoosa	6.1	16.0	57.8	15.4	1,437.0	7	3
AL Tuscaloosa	5.1	20.1	69.6	13.8	543.3	3	3
AL Walker	9.3	17.3	56.0	10.4	1,440.4	2	3
AL Winston	11.2	19.8	48.8	13.9	2,455.6	7	3
GA Total	5.4	14.3	70.9	12.7	626.7		
GA App. Part	5.6	9.8	67.5	10.2	1,242.2		
GA Banks	5.5	15.1	56.6	8.6	1,716.7	8	3
GA Barrow	8.1	14.7	58.8	9.6	2,475.0	1	3
GA Bartow	8.5	10.7	58.7	10.4	1,644.1	6	3
GA Carroll	6.2	14.4	60.5	11.4	952.0	6	3
GA Catoosa	4.2	12.0	63.8	7.6	1,465.5	2	3
GA Chattooga	7.7	14.6	50.1	11.4	5,550.0	7	2
GA Cherokee	4.4	6.1	75.2	9.0	2,652.9	1	4
GA Dade	6.2	14.6	55.3	9.8	2,183.3	2	3
GA Dawson	8.5	12.8	60.1	16.8	4,700.0	8	3
GA Douglas	4.8	6.6	72.3	8.7	1,269.6	1	5
GA Fannin	7.4	17.2	55.8	10.8	2,666.7	9	3
GA Floyd	7.1	13.6	63.9	13.6	414.8	5	3
GA Forsyth	4.8	6.8	67.6	7.2	2,205.0	1	4
GA Franklin	6.4	16.5	54.1	12.5	1,284.6	8	3
GA Gilmer	6.8	16.6	52.3	20.9	1,675.0	9	3
GA Gordon	6.2	11.1	58.4	10.5	1,350.0	7	3
GA Gwinnett	4.3	4.0	86.7	8.1	1,341.8	0	5
GA Habersham	4.3	11.6	59.0	12.6	2,123.1	7	3
GA Hall	5.6	10.6	65.1	8.3	636.0	6	4
GA Haralson	7.8	14.4	56.0	13.9	1,466.7	6	3
GA Heard	6.0	19.1	49.1	21.6	4,300.0	8	3
GA Jackson	5.6	14.1	54.5	12.5	2,500.0	3	3
GA Lumpkin	3.9	15.3	60.2	10.9	1,123.1	7	3
GA Madison	6.1	15.7	59.7	9.4	4,220.0	3	3
GA Murray	7.2	11.3	52.1	11.7	3,728.6	9	3
GA Paulding	6.1	8.8	64.1	9.9	5,200.0	1	3
GA Pickens	10.0	12.8	56.8	21.2	2,057.1	8	3
GA Polk	11.6	16.3	51.8	10.7	1,988.2	6	3
GA Rabun	4.9	13.6	62.7	11.1	1,160.0	9	3

continued

Selected Characteristics of Appalachia and Appalachian Counties (continued)

Summary Level	1990 Census Population	% Change Pop. 1970-1980	% Change Pop. 1980-1990	1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
GA Stephens	23,300	7.4	6.9	15.0	6,882	13,487
GA Towns	6,800	21.7	21.4	23.8	5,170	12,368
GA Union	12,000	38.2	27.7	18.4	4,305	11,595
GA Walker	58,300	11.7	3.2	13.3	7,073	13,149
GA White	13,000	29.5	28.7	14.9	5,525	15,078
GA Whitfield	72,500	19.6	10.2	9.9	8,078	17,860
KY Total	3,685,100	13.8	0.7	12.7	7,645	15,012
KY App. Part	1,045,300	23.1	-2.9	12.5	6,086	11,759
KY Adair	15,400	16.9	1.3	15.6	5,053	11,803
KY Bath	39,700	8.7	-3.0	15.2	5,669	11,223
KY Bell	31,500	10.3	-8.2	13.3	6,508	10,728
KY Boyd	51,200	6.1	-7.7	14.8	9,473	16,824
KY Breathitt	15,700	19.7	-7.6	10.9	5,254	10,531
KY Carter	24,300	26.8	-3.2	12.8	4,766	10,370
KY Casey	14,200	13.8	-4.1	15.1	4,295	10,241
KY Clark	29,500	17.4	4.2	12.5	8,090	14,739
KY Clay	21,700	23.9	-4.8	10.7	5,134	8,693
KY Clinton	9,100	13.4	-2.2	15.3	3,956	8,875
KY Cumberland	6,800	7.4	-6.8	18.0	4,960	9,900
KY Elliott	6,500	16.9	-5.8	12.4	4,499	7,880
KY Estill	14,600	13.3	0.7	13.8	5,972	10,053
KY Fleming	12,300	8.8	0.0	15.5	5,387	11,511
KY Floyd	43,600	35.9	-10.7	11.5	6,162	12,571
KY Garrard	11,600	16.0	6.4	15.4	6,894	13,328
KY Green	10,400	6.8	-5.5	17.9	5,866	12,137
KY Greenup	36,700	18.1	-6.1	12.2	7,332	14,002
KY Harlan	36,600	12.6	-12.6	13.0	6,738	11,610
KY Jackson	12,000	21.2	0.0	13.2	4,131	8,391
KY Johnson	23,200	39.4	-4.9	11.8	6,589	12,273
KY Knott	17,900	21.8	0.0	10.5	5,353	9,185
KY Knox	29,700	27.4	-1.7	13.0	4,956	9,941
KY Laurel	43,400	42.3	11.3	11.4	5,758	12,069
KY Lawrence	14,000	31.8	-0.7	13.0	5,788	9,755
KY Lee	7,400	18.2	-5.1	14.4	4,484	8,788
KY Leslie	13,600	28.4	-8.7	9.3	4,707	9,929
KY Letcher	27,000	32.9	-12.1	11.7	6,030	10,892
KY Lewis	13,000	17.9	-10.3	13.5	4,607	10,513
KY Lincoln	20,000	14.4	4.7	14.2	5,380	10,316
KY Madison	57,500	25.1	7.7	10.3	6,248	12,672

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate † 1984-1988	1990 Pop. per Patient-Care Doctor	1988 USDA‡, ♦ Rural/ Urban Code	ARC §, ♦ 1988 Distressed Counties
GA Stephens	6.9	17.0	60.1	13.6	776.7	7	3
GA Towns	3.7	14.0	58.2	13.6	1,700.0	9	3
GA Union	4.7	18.3	58.7	13.2	1,500.0	9	3
GA Walker	6.3	12.8	58.3	13.8	3,886.7	2	3
GA White	4.5	12.5	62.9	15.8	1,625.0	9	3
GA Whitfield	4.9	11.1	59.8	10.1	725.0	4	4
KY Total	5.8	18.5	64.6	10.6	633.7		
KY App. Part	7.7	28.4	51.5	11.2	1,183.8		
KY Adair	6.4	25.1	46.3	7.9	1,400.0	7	2
KY Bath	9.9	27.3	46.3	11.1	1,616.7	8	1
KY Bell	9.1	36.2	46.7	8.7	670.2	7	1
KY Boyd	5.8	16.5	68.9	10.7	487.6	2	3
KY Breathitt	9.1	39.5	47.8	10.2	3,140.0	7	1
KY Carter	13.5	26.8	51.3	13.4	4,860.0	2	1
KY Casey	7.7	29.4	43.1	16.1	3,550.0	9	1
KY Clark	6.7	17.7	65.1	9.0	1,053.6	2	3
KY Clay	8.2	40.2	38.9	13.3	2,411.1	9	1
KY Clinton	10.0	38.1	44.4	5.0	3,033.3	9	1
KY Cumberland	7.4	31.6	39.5	19.6	3,400.0	9	3
KY Elliott	17.3	38.0	44.0	5.6	3,250.0	8	1
KY Estill	12.2	29.0	46.5	11.1	2,920.0	6	1
KY Fleming	7.6	25.4	53.8	17.8	2,460.0	7	2
KY Floyd	6.9	31.2	50.8	10.4	927.7	7	1
KY Garrard	7.3	18.1	54.3	7.8	2,320.0	6	3
KY Green	6.1	21.6	49.0	11.7	1,155.6	9	2
KY Greenup	6.0	17.6	64.7	10.5	2,446.7	2	3
KY Harlan	7.6	33.1	49.5	12.7	1,045.7	7	1
KY Jackson	10.4	38.2	38.3	7.3	6,000.0	9	1
KY Johnson	7.1	28.7	54.7	5.8	966.7	7	1
KY Knott	8.6	40.4	45.1	9.9	3,580.0	9	1
KY Knox	7.0	38.9	46.6	13.9	2,970.0	7	2
KY Laurel	6.3	24.8	52.7	12.8	2,170.0	7	2
KY Lawrence	9.7	36.0	46.4	21.8	1,166.7	8	1
KY Lee	8.3	37.4	43.4	9.3	1,850.0	9	1
KY Leslie	5.7	35.6	40.4	14.4	1,511.1	9	1
KY Letcher	7.7	31.8	45.6	13.3	1,080.0	7	1
KY Lewis	9.9	30.7	45.4	7.7	6,500.0	9	1
KY Lincoln	8.5	27.2	50.4	14.4	2,857.1	7	1
KY Madison	5.1	21.2	64.8	8.8	809.9	4	3

continued

Selected Characteristics of Appalachia and Appalachian Counties (continued)

Summary Level	1990 Census Population	% Change Pop. 1970-1980	% Change Pop. 1980-1990	1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
KY Magoffin	13,100	28.6	-3.0	10.1	4,868	8,843
KY Martin	12,500	49.5	-10.1	8.7	7,043	12,062
KY McCreary	15,600	24.8	0.0	11.2	4,058	7,663
KY Menifee	5,100	27.5	0.0	12.1	3,872	8,206
KY Monroe	11,400	6.9	-8.1	16.1	5,212	12,208
KY Montgomery	19,600	30.7	-2.0	13.0	6,488	13,215
KY Morgan	11,600	19.8	-4.1	12.5	4,550	9,497
KY Owsley	5,000	11.8	-12.3	15.6	3,779	8,551
KY Perry	30,300	31.5	-10.4	10.5	6,477	13,563
KY Pike	72,600	33.0	-10.5	10.7	7,298	13,109
KY Powell	11,700	44.2	5.4	10.5	4,984	9,883
KY Pulaski	49,500	30.1	8.1	14.2	6,168	12,942
KY Rockcastle	14,800	13.8	5.7	13.3	4,451	10,600
KY Rowan	20,400	12.4	7.4	10.0	5,493	10,397
KY Russell	14,700	30.5	7.3	16.1	4,810	12,726
KY Wayne	17,500	19.7	2.9	13.9	4,657	9,527
KY Whitley	33,300	38.6	-0.3	12.9	6,506	12,390
KY Wolfe	6,500	19.6	-3.0	11.8	4,460	8,991
MD Total	4,781,100	7.5	13.4	10.8	10,405	21,952
MD App. Part	224,400	5.2	2.0	15.4	7,824	15,405
MD Allegany	74,900	-4.2	-7.0	18.5	7,627	14,786
MD Garrett	28,100	23.8	6.0	13.8	6,330	13,172
MD Washington	121,400	9.0	7.3	13.8	8,276	16,238
MS Total	2,573,500	13.7	2.1	12.5	6,684	12,834
MS App. Part	510,600	15.0	2.5	13.3	6,241	12,241
MS Alcorn	31,700	21.3	-3.9	15.4	6,842	12,691
MS Benton	8,000	9.3	-2.4	14.9	4,740	10,183
MS Calhoun	14,900	7.5	-5.1	16.9	5,381	10,991
MS Chickasaw	18,100	6.5	1.1	13.8	6,028	11,672
MS Choctaw	9,100	5.9	1.1	14.6	5,379	9,735
MS Clay	21,100	12.2	0.0	13.3	6,467	12,291
MS Itawamba	20,000	21.3	-2.4	15.4	5,661	11,497
MS Kemper	10,400	-1.0	3.0	15.7	4,598	8,984
MS Lee	65,600	23.9	14.9	11.6	7,899	14,627
MS Lowndes	59,300	15.5	3.5	10.2	7,213	14,000
MS Marshall	30,400	22.1	3.8	11.5	4,408	11,434
MS Monroe	36,600	6.7	0.5	14.3	6,321	12,312
MS Noxubee	12,600	-7.0	-4.5	13.3	4,635	8,942

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate† 1984-1988	1990 Pop. per Patient-Care Doctor	1988 USDA‡,♦ Rural/ Urban Code	ARC§,♦ 1988 Distressed Counties
KY Magoffin	14.9	42.5	38.2	10.8	3,275.0	9	1
KY Martin	7.8	35.4	44.4	13.8	2,083.3	9	1
KY McCreary	14.1	45.5	40.2	8.6	1,950.0	9	1
KY Menifee	10.9	35.0	46.0	20.3	5,100.0	9	1
KY Monroe	6.3	26.9	47.1	11.7	1,900.0	7	2
KY Montgomery	11.6	21.0	56.1	7.0	980.0	6	1
KY Morgan	9.9	38.8	44.1	18.4	1,450.0	9	1
KY Owsley	8.5	52.1	35.5	15.7	*	9	1
KY Perry	7.2	32.1	47.6	11.0	704.7	7	1
KY Pike	7.2	25.4	50.2	10.8	1,052.2	7	1
KY Powell	9.1	26.2	50.1	14.5	3,900.0	6	1
KY Pulaski	8.2	22.7	56.2	11.5	900.0	7	1
KY Rockcastle	7.0	30.7	44.9	5.2	1,850.0	9	1
KY Rowan	5.9	28.9	57.9	16.0	510.0	7	2
KY Russell	5.9	25.6	50.2	3.5	1,837.5	9	1
KY Wayne	8.3	37.3	44.6	7.5	1,590.9	7	1
KY Whitley	7.2	33.0	53.0	11.6	640.4	7	1
KY Wolfe	15.3	44.3	42.8	14.7	3,250.0	9	1
MD Total	4.7	8.1	78.4	11.6	371.1		
MD App. Part	7.6	11.8	69.7	9.8	688.3		
MD Allegany	8.8	16.5	71.0	9.1	499.3	3	3
MD Garrett	8.9	14.7	68.4	14.4	1,277.3	8	2
MD Washington	6.7	9.3	69.3	9.1	788.3	3	3
MS Total	7.4	24.5	64.3	13.3	783.9		
MS App. Part	8.2	22.0	59.3	12.8	1,179.2		
MS Alcorn	10.1	20.8	56.3	7.6	1,093.1	7	2
MS Benton	11.2	29.7	46.4	6.3	*	9	1
MS Calhoun	9.1	21.5	52.8	6.6	2,980.0	9	2
MS Chickasaw	14.1	21.3	52.9	20.6	2,262.5	7	1
MS Choctaw	10.9	25.0	57.6	10.8	4,550.0	9	1
MS Clay	9.9	25.9	60.4	14.9	1,623.1	7	1
MS Itawamba	6.8	15.6	49.0	12.3	5,000.0	7	3
MS Kemper	10.7	35.1	56.3	12.2	3,466.7	9	1
MS Lee	6.5	15.4	67.8	15.5	475.4	5	3
MS Lowndes	6.3	22.1	69.0	10.2	801.4	5	3
MS Marshall	11.9	30.0	51.7	15.2	3,377.8	6	1
MS Monroe	8.1	21.2	55.6	12.5	1,307.1	7	2
MS Noxubee	12.8	41.4	49.6	15.0	3,150.0	9	1

continued

Selected Characteristics of Appalachia and Appalachian Counties (continued)

Summary Level	1990 Census Population	% Change Pop. 1970-1980	% Change Pop. 1980-1990	1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
MS Oktibbeha	38,400	25.0	6.7	8.9	6,089	11,234
MS Pontotoc	22,200	20.1	6.2	14.3	5,682	12,763
MS Prentiss	23,300	18.8	-2.9	14.2	5,614	11,449
MS Tippah	19,500	17.6	4.3	15.4	5,984	11,818
MS Tishomingo	17,700	22.7	-3.8	16.8	6,477	11,231
MS Union	22,100	14.2	1.8	15.4	6,414	11,957
MS Webster	10,200	2.0	-1.0	17.6	6,144	11,372
MS Winston	19,400	6.0	-0.5	15.4	5,694	11,489
NC Total	6,628,900	15.8	12.7	12.1	7,761	16,325
NC App. Part	1,306,700	17.4	7.3	14.9	7,596	16,165
NC Alexander	27,500	28.2	10.0	11.0	6,484	14,995
NC Alleghany	9,600	18.5	0.0	18.6	6,120	12,950
NC Ashe	22,200	13.8	-0.4	17.1	5,691	12,468
NC Avery	14,900	13.4	3.5	14.6	5,072	12,517
NC Buncombe	174,800	11.0	8.6	16.1	7,984	16,934
NC Burke	75,700	20.2	4.4	13.0	7,138	15,096
NC Caldwell	70,700	19.4	4.4	12.1	6,768	14,945
NC Cherokee	20,200	16.0	6.9	18.9	5,239	12,271
NC Clay	7,200	29.4	9.1	20.2	5,047	11,992
NC Davie	27,900	30.9	13.4	13.8	7,222	18,339
NC Forsyth	265,900	13.7	9.1	12.2	9,787	20,645
NC Graham	7,200	9.1	0.0	16.1	6,107	9,223
NC Haywood	46,900	11.2	0.9	18.2	7,238	14,235
NC Henderson	69,300	37.2	18.3	21.8	8,300	18,175
NC Jackson	26,800	19.4	3.9	13.8	6,004	12,870
NC Macon	23,500	27.8	16.3	22.5	6,608	14,093
NC Madison	17,000	5.0	1.2	16.7	5,396	12,190
NC McDowell	35,700	14.7	1.7	14.4	7,200	12,466
NC Mitchell	14,400	7.5	0.0	17.7	6,243	12,188
NC Polk	14,400	11.1	10.8	24.7	8,589	20,106
NC Rutherford	56,900	13.7	5.8	15.6	6,894	14,198
NC Stokes	37,200	39.1	12.4	11.5	6,262	14,257
NC Surry	61,700	15.8	3.9	14.8	7,195	15,460
NC Swain	11,300	30.4	9.7	15.3	5,781	9,930
NC Transylvania	25,500	18.8	9.0	18.5	7,412	15,435
NC Watauga	37,000	35.5	16.7	10.6	6,040	12,734
NC Wilkes	59,400	18.6	1.2	13.2	7,171	14,699
NC Yadkin	30,500	15.4	7.4	14.8	7,650	15,261

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate† 1984-1988	1990 Pop. per Patient-Care Doctor	1988 USDA‡,♦ Rural/ Urban Code	ARC§,♦ 1988 Distressed Counties
MS Oktibbeha	4.8	30.1	73.0	11.9	1,066.7	7	3
MS Pontotoc	5.5	17.2	57.4	9.0	1,850.0	7	3
MS Prentiss	7.7	21.5	52.9	9.5	1,941.7	7	2
MS Tippah	8.0	22.6	54.4	21.4	1,772.7	7	1
MS Tishomingo	14.9	20.3	55.0	14.9	1,361.5	6	3
MS Union	6.7	16.4	57.3	11.2	1,300.0	7	3
MS Webster	7.6	24.4	58.6	11.1	2,040.0	9	2
MS Winston	8.1	26.6	59.1	13.2	1,940.0	7	1
NC Total	4.1	12.5	70.0	12.0	596.9		
NC App. Part	4.3	12.1	67.1	10.8	557.9		
NC Alexander	3.8	9.8	59.0	11.3	3,055.6	3	5
NC Alleghany	3.9	20.1	52.6	13.4	1,600.0	9	3
NC Ashe	5.8	18.4	55.6	12.4	1,585.7	9	3
NC Avery	4.1	14.6	62.2	3.1	620.8	9	3
NC Buncombe	3.3	11.4	74.5	9.8	405.6	3	3
NC Burke	3.9	10.1	60.1	8.4	707.5	3	4
NC Caldwell	4.3	10.8	56.8	11.4	1,159.0	6	3
NC Cherokee	8.8	20.4	59.9	7.3	1,262.5	9	2
NC Clay	5.7	17.9	62.9	8.1	1,440.0	9	3
NC Davie	4.6	8.4	69.6	9.1	1,550.0	2	4
NC Forsyth	3.9	10.5	77.6	13.0	249.2	2	4
NC Graham	19.1	24.9	56.9	4.4	1,800.0	9	1
NC Haywood	5.2	12.7	68.0	8.0	732.8	6	3
NC Henderson	3.1	10.5	76.2	10.3	630.0	6	4
NC Jackson	4.2	16.7	68.7	11.7	515.4	9	3
NC Macon	3.7	16.5	66.7	11.0	783.3	7	3
NC Madison	4.4	20.4	56.4	7.7	2,125.0	8	3
NC McDowell	6.5	11.4	58.5	14.9	1,373.1	6	3
NC Mitchell	6.4	16.0	55.3	5.5	900.0	9	3
NC Polk	3.1	9.6	69.6	19.9	720.0	9	3
NC Rutherford	5.3	12.3	59.4	8.8	1,293.2	6	3
NC Stokes	4.4	9.8	62.8	7.4	4,650.0	2	3
NC Surry	4.7	11.4	57.3	14.7	1,312.8	6	3
NC Swain	10.3	27.6	59.0	11.7	941.7	9	1
NC Transylvania	3.1	13.5	72.1	11.1	910.7	6	3
NC Watauga	2.8	21.5	72.0	9.5	649.1	7	3
NC Wilkes	3.9	13.3	54.1	11.5	1,563.2	7	3
NC Yadkin	4.5	12.0	58.9	9.3	1,906.3	2	3

continued

Selected Characteristics of Appalachia and Appalachian Counties (continued)

Summary Level	1990 Census Population	% Change Pop. 1970-1980	% Change Pop. 1980-1990	1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
NC Yancey	15,400	18.3	3.4	17.2	5,152	12,068
NY Total	17,990,700	-3.7	2.5	13.1	10,293	22,143
NY App. Part	1,088,600	2.5	0.5	14.0	7,921	15,383
NY Allegany	50,500	11.4	-2.3	13.4	6,466	12,590
NY Broome	212,200	-3.7	-0.7	15.0	9,146	18,058
NY Cattaraugus	84,200	5.0	-1.8	14.0	7,064	13,698
NY Chautauqua	141,900	-0.3	-3.4	15.7	8,150	15,197
NY Chemung	95,200	-3.8	-2.6	15.1	8,420	15,885
NY Chenango	51,800	6.5	5.1	14.0	7,286	14,604
NY Cortland	49,000	6.6	0.4	12.1	7,243	14,164
NY Delaware	47,200	4.7	0.9	16.4	7,118	14,232
NY Otsego	60,500	5.2	2.4	15.1	7,188	15,503
NY Schoharie	31,900	20.2	7.4	14.2	6,119	14,273
NY Schuyler	18,700	6.0	5.6	14.2	7,103	12,797
NY Steuben	99,100	-0.5	-0.1	14.6	8,250	14,768
NY Tioga	52,300	7.1	5.0	10.9	7,975	15,272
NY Tompkins	94,100	13.1	8.0	9.0	7,632	15,271
OH Total	10,847,100	1.4	0.5	13.0	9,434	17,586
OH App. Part	1,372,800	11.3	-0.2	13.7	7,542	13,442
OH Adams	25,400	28.6	4.5	13.5	5,351	10,063
OH Athens	59,500	2.7	5.5	9.8	5,785	11,586
OH Belmont	71,100	2.2	-13.9	18.7	8,862	14,166
OH Brown	35,000	19.9	9.7	12.8	7,059	13,011
OH Carroll	26,500	19.1	3.5	13.7	7,099	13,033
OH Clermont	150,200	34.1	16.9	8.7	8,484	16,231
OH Columbiana	108,300	4.9	-4.7	14.9	7,866	12,597
OH Coshocton	35,400	7.8	-1.7	14.4	8,275	13,726
OH Gallia	31,000	19.4	3.0	12.8	7,347	12,832
OH Guernsey	39,000	11.7	-7.1	14.9	7,168	12,841
OH Harrison	16,100	7.1	-11.5	17.3	7,390	10,851
OH Highland	35,700	15.9	6.6	15.0	6,947	13,255
OH Hocking	25,500	19.7	4.9	13.3	6,621	12,334
OH Holmes	32,800	27.8	11.6	10.8	5,771	11,016
OH Jackson	30,200	12.9	-1.3	14.0	6,202	11,492
OH Jefferson	80,300	-4.8	-12.3	17.2	9,225	14,583
OH Lawrence	61,800	12.3	-3.1	13.3	7,102	11,841
OH Meigs	23,000	19.8	-2.5	15.0	6,797	11,562
OH Monroe	15,500	10.8	-10.9	15.6	6,887	13,192

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate† 1984-1988	1990 Pop. per Patient-Care Doctor	1988 USDA‡,♦ Rural/ Urban Code	ARC§,♦ 1988 Distressed Counties
NC Yancey	4.7	18.7	60.7	8.0	3,850.0	8	3
NY Total	5.2	12.7	74.8	10.8	363.7		
NY App. Part	4.7	12.2	77.3	9.3	697.4		
NY Allegany	5.9	14.8	76.9	8.2	1,402.8	7	3
NY Broome	4.1	10.5	78.9	11.0	499.3	2	4
NY Cattaraugus	6.2	14.0	74.5	7.2	859.2	4	3
NY Chautauqua	5.4	13.8	74.4	9.1	865.2	4	3
NY Chemung	4.4	11.4	77.2	8.7	503.7	3	3
NY Chenango	6.1	11.7	75.5	9.2	1,328.2	6	3
NY Cortland	5.5	12.7	76.8	6.0	1,042.6	4	3
NY Delaware	5.3	12.8	74.0	11.2	1,151.2	6	3
NY Otsego	4.0	13.9	77.7	7.8	305.6	6	3
NY Schoharie	5.0	11.5	73.7	9.6	1,519.0	6	3
NY Schuyler	5.7	11.2	74.2	7.3	984.2	8	3
NY Steuben	5.5	13.5	75.0	10.2	962.1	4	3
NY Tioga	4.4	9.3	80.6	7.6	1,584.8	2	4
NY Tompkins	2.2	18.9	87.2	11.7	635.8	5	3
OH Total	5.7	12.2	75.7	10.1	553.8		
OH App. Part	7.0	16.9	69.2	9.4	1,357.9		
OH Adams	12.0	28.5	58.4	8.3	1,953.8	7	1
OH Athens	5.9	28.7	74.6	8.4	2,203.7	4	3
OH Belmont	5.7	17.4	72.3	9.7	1,110.9	3	3
OH Brown	7.9	14.2	64.9	10.2	2,187.5	6	3
OH Carroll	6.2	11.7	71.5	11.7	5,300.0	2	3
OH Clermont	5.0	8.7	72.8	7.4	1,877.5	1	3
OH Columbiana	5.9	15.9	71.8	9.9	1,370.9	4	3
OH Coshocton	6.5	13.2	71.3	9.6	1,770.0	7	3
OH Gallia	7.7	22.5	64.2	7.4	484.4	6	3
OH Guernsey	8.7	17.5	71.4	9.4	886.4	7	3
OH Harrison	11.1	19.7	69.8	8.6	1,341.7	6	3
OH Highland	8.0	16.5	66.5	6.5	1,983.3	7	3
OH Hocking	9.4	15.7	67.8	12.6	2,550.0	6	3
OH Holmes	4.7	17.2	46.9	8.2	1,640.0	7	3
OH Jackson	8.5	24.2	60.9	8.5	4,314.3	7	2
OH Jefferson	6.1	17.1	71.9	10.5	912.5	3	3
OH Lawrence	6.2	23.5	65.9	10.9	2,131.0	2	3
OH Meigs	7.5	26.0	64.0	11.2	2,875.0	6	2
OH Monroe	10.8	21.5	69.4	5.0	7,750.0	6	3

continued

Selected Characteristics of Appalachia and Appalachian Counties (continued)

Summary Level	1990 Census Population	% Change Pop. 1970-1980	% Change Pop. 1980-1990	1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
OH Morgan	14,200	15.4	0.0	15.0	7,500	12,978
OH Muskingum	82,100	7.2	-1.4	13.8	7,963	14,963
OH Noble	11,300	8.7	0.0	15.1	6,246	12,407
OH Perry	31,600	13.1	1.9	12.9	6,424	11,688
OH Pike	24,200	19.4	6.1	13.6	5,939	12,013
OH Ross	69,300	6.2	6.6	12.4	7,674	13,476
OH Scioto	80,300	10.0	-5.0	14.9	6,630	12,674
OH Tuscarawas	84,100	9.7	-0.6	14.9	7,982	14,958
OH Vinton	11,100	23.4	-4.3	13.7	5,633	11,048
OH Washington	62,300	12.4	-3.1	13.6	7,946	14,645
PA Total	11,881,700	0.6	0.2	15.4	9,401	18,696
PA App. Part	5,769,400	1.1	-3.8	16.7	8,759	16,775
PA Allegheny	1,336,400	-9.7	-7.8	17.4	10,938	20,681
PA Armstrong	73,500	2.9	-5.5	17.5	7,753	16,738
PA Beaver	186,100	-2.0	-9.0	16.9	9,126	15,162
PA Bedford	47,900	10.6	2.4	15.3	6,373	12,924
PA Blair	130,500	0.9	-4.5	17.0	7,563	14,779
PA Bradford	61,000	8.4	-3.0	14.7	7,224	15,246
PA Butler	152,000	15.5	2.8	13.5	8,289	17,251
PA Cambria	163,000	-1.9	-11.1	18.8	8,221	14,473
PA Cameron	5,900	-5.6	-11.9	18.6	8,347	14,900
PA Carbon	56,800	5.5	6.6	18.5	8,373	15,177
PA Centre	123,800	13.7	9.8	9.0	7,104	15,476
PA Clarion	41,700	13.3	-3.9	13.9	7,766	13,989
PA Clearfield	78,100	12.2	-6.6	16.6	7,803	14,415
PA Clinton	37,200	3.7	-4.6	16.0	7,339	13,115
PA Columbia	63,200	12.5	1.9	15.8	7,242	14,406
PA Crawford	86,200	9.3	-3.0	15.4	7,499	14,417
PA Elk	34,900	1.6	-8.9	16.0	8,388	16,872
PA Erie	275,600	6.1	-1.5	13.8	8,750	16,331
PA Fayette	145,400	3.0	-8.8	17.9	7,299	14,051
PA Forest	4,800	4.1	-5.9	20.2	7,265	13,115
PA Fulton	13,800	18.5	7.8	13.0	6,329	14,393
PA Greene	39,600	12.5	-2.2	16.4	6,909	12,645
PA Huntingdon	44,200	8.2	4.5	13.5	6,498	12,158
PA Indiana	90,000	16.1	-2.5	13.8	7,771	13,841
PA Jefferson	46,100	10.8	-4.6	17.2	7,752	14,809
PA Juniata	20,600	15.0	7.3	14.5	7,677	14,626
PA Lackawanna	219,000	-2.6	-3.9	19.7	8,217	16,963

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate† 1984-1988	1990 Pop. per Patient-Care Doctor	1988 USDA‡,♦ Rural/ Urban Code	ARC§,♦ 1988 Distressed Counties
OH Morgan	8.7	21.2	71.6	12.4	4,733.3	9	3
OH Muskingum	8.5	14.7	71.1	9.3	695.8	4	3
OH Noble	8.5	16.4	69.9	10.1	11,300.0	8	3
OH Perry	11.9	19.1	68.6	9.4	6,320.0	6	3
OH Pike	9.7	26.6	60.8	14.4	1,423.5	7	1
OH Ross	8.1	17.7	67.6	11.8	1,066.2	4	3
OH Scioto	8.7	25.8	63.8	9.5	1,131.0	4	2
OH Tuscarawas	6.4	11.1	71.9	9.0	1,201.4	4	3
OH Vinton	9.1	23.6	58.7	12.2	*	9	2
OH Washington	6.0	13.7	77.5	8.2	1,132.7	3	3
PA Total	5.4	10.8	74.7	10.4	463.9		
PA App. Part	6.2	12.1	75.0	9.6	548.6		
PA Allegheny	4.2	11.5	79.0	11.2	281.7	0	3
PA Armstrong	8.1	12.8	71.1	9.7	1,289.5	6	3
PA Beaver	7.8	13.1	74.9	10.2	989.9	1	3
PA Bedford	9.2	13.6	68.5	9.5	1,842.3	6	3
PA Blair	7.2	14.1	75.0	10.2	633.5	3	3
PA Bradford	5.5	13.3	75.7	7.3	352.6	6	3
PA Butler	5.5	9.7	78.6	9.5	1,288.1	4	3
PA Cambria	7.7	14.0	71.2	8.8	576.0	2	3
PA Cameron	7.7	11.3	73.1	4.2	1,180.0	7	3
PA Carbon	7.8	9.4	69.4	7.2	1,420.0	2	3
PA Centre	5.3	18.2	83.6	8.6	732.5	2	3
PA Clarion	8.9	18.1	73.1	6.5	4,170.0	7	3
PA Clearfield	9.9	13.9	70.2	11.1	964.2	6	3
PA Clinton	9.8	15.4	72.5	10.5	1,062.9	6	3
PA Columbia	6.7	10.6	73.1	8.0	877.8	2	3
PA Crawford	7.1	15.5	74.1	12.1	990.8	4	3
PA Elk	6.3	9.5	74.9	8.1	943.2	7	3
PA Erie	5.5	12.9	77.5	10.8	613.8	2	3
PA Fayette	7.9	20.9	67.8	10.0	1,182.1	1	2
PA Forest	9.1	11.8	70.5	7.7	4,800.0	9	3
PA Fulton	7.5	12.2	64.0	8.6	4,600.0	8	3
PA Greene	9.1	21.4	68.0	12.2	1,237.5	6	3
PA Huntingdon	10.0	13.4	71.2	5.2	1,133.3	6	3
PA Indiana	8.8	18.7	74.0	11.2	1,058.8	4	3
PA Jefferson	7.5	13.6	72.6	7.9	1,152.5	7	3
PA Juniata	10.4	9.8	65.2	10.9	4,120.0	8	3
PA Lackawanna	6.7	10.7	73.3	8.7	530.3	2	3

continued

Selected Characteristics of Appalachia and Appalachian Counties (continued)

Summary Level	1990 Census Population	% Change Pop. 1970-1980	% Change Pop. 1980-1990	1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
PA Lawrence	96,200	-0.3	-10.3	18.5	7,821	14,774
PA Luzerne	328,100	0.2	-4.4	19.7	8,218	16,405
PA Lycoming	118,700	4.6	0.3	15.1	8,049	15,778
PA McKean	47,100	-2.5	-6.9	16.7	8,418	14,408
PA Mercer	121,000	0.9	-5.7	17.2	8,497	15,177
PA Mifflin	46,200	3.8	-1.5	16.0	7,115	13,509
PA Monroe	95,700	52.9	37.9	13.1	8,220	17,592
PA Montour	17,700	1.8	6.0	16.5	7,725	18,116
PA Northumberland	96,800	1.3	-3.6	18.9	7,862	14,570
PA Perry	41,200	25.3	15.4	11.1	7,156	14,941
PA Pike	28,000	55.1	53.0	15.6	6,946	19,145
PA Potter	16,700	8.6	-5.6	16.5	6,399	13,897
PA Schuylkill	152,600	0.4	-5.0	20.0	7,750	15,853
PA Snyder	36,700	14.7	9.2	12.6	7,133	17,610
PA Somerset	78,200	7.0	-3.7	16.9	7,857	14,270
PA Sullivan	6,100	6.8	-3.2	20.9	6,099	14,335
PA Susquehanna	40,400	10.5	6.6	15.3	6,296	13,987
PA Tioga	41,100	3.3	0.2	15.0	6,967	12,993
PA Union	36,200	15.4	10.0	12.6	7,477	15,297
PA Venango	59,400	3.4	-7.8	15.0	8,764	16,267
PA Warren	45,100	-0.4	-4.9	15.6	8,602	16,918
PA Washington	204,600	2.9	-5.8	17.5	8,872	16,625
PA Wayne	39,900	19.3	13.4	17.0	6,942	16,246
PA Westmoreland	370,300	4.1	-5.6	17.1	8,991	17,069
PA Wyoming	28,100	38.9	6.4	12.6	6,580	15,503
SC Total	3,487,000	20.6	11.7	11.4	7,310	15,191
SC App. Part	888,100	20.7	12.1	12.5	7,916	16,179
SC Anderson	145,200	26.5	9.0	13.6	7,285	14,205
SC Cherokee	44,500	11.4	8.5	13.0	7,332	14,683
SC Greenville	320,200	19.7	11.2	11.9	8,654	17,874
SC Oconee	57,500	19.4	18.3	13.7	6,927	15,682
SC Pickens	93,900	34.6	18.4	11.2	6,721	14,903
SC Spartanburg	226,800	16.2	12.3	12.7	8,012	15,776
TN Total	4,876,900	17.1	6.2	12.7	7,667	15,901
TN App. Part	2,146,800	19.7	3.5	13.7	7,215	14,757
TN Anderson	68,300	11.6	1.5	15.4	9,671	16,402
TN Bledsoe	9,700	23.4	2.1	12.0	4,546	10,367

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate † 1984-1988	1990 Pop. per Patient-Care Doctor	1988 USDA‡, ♦ Rural/ Urban Code	ARC §, ♦ 1988 Distressed Counties
PA Lawrence	5.7	13.9	73.0	9.3	1,249.4	4	3
PA Luzerne	7.2	11.2	72.0	8.2	586.9	2	3
PA Lycoming	7.2	11.5	74.5	8.0	527.6	2	3
PA McKean	6.9	14.9	75.4	8.8	1,121.4	7	3
PA Mercer	5.3	12.8	75.1	7.7	834.5	3	3
PA Mifflin	8.2	13.4	68.2	7.8	783.1	7	3
PA Monroe	6.8	7.3	78.0	7.9	817.9	2	4
PA Montour	5.3	8.5	75.2	12.8	51.6	6	4
PA Northumberland	8.6	11.6	68.5	5.7	1,257.1	4	3
PA Perry	5.8	7.5	72.3	6.6	4,120.0	2	4
PA Pike	5.8	7.1	79.2	7.5	2,800.0	8	4
PA Potter	7.2	14.9	73.8	12.0	878.9	7	3
PA Schuylkill	7.8	10.7	68.4	9.1	1,082.3	4	3
PA Snyder	7.5	11.0	64.4	7.1	1,595.7	7	3
PA Somerset	7.5	14.3	68.9	10.0	965.4	2	3
PA Sullivan	5.5	18.0	70.2	3.3	6,100.0	8	3
PA Susquehanna	7.8	12.1	76.0	8.4	1,442.9	8	3
PA Tioga	7.2	14.6	72.9	7.0	1,141.7	6	3
PA Union	5.5	10.3	73.1	9.1	635.1	6	3
PA Venango	5.9	15.1	74.2	10.9	667.4	4	3
PA Warren	4.9	9.6	76.6	11.5	850.9	6	3
PA Washington	5.5	12.8	73.2	10.0	905.3	1	3
PA Wayne	6.9	11.3	74.2	9.8	752.8	6	3
PA Westmoreland	5.7	10.7	77.7	7.7	743.6	1	3
PA Wyoming	6.6	11.1	77.6	9.0	1,040.7	2	3
SC Total	4.7	14.8	68.3	13.4	674.5		
SC App. Part	4.3	11.2	66.3	12.7	666.2		
SC Anderson	5.4	12.0	64.0	12.7	748.5	3	3
SC Cherokee	5.7	14.9	57.2	12.3	1,390.6	6	3
SC Greenville	3.6	10.5	71.6	13.3	517.3	2	4
SC Oconee	5.2	11.4	63.4	12.5	871.2	6	3
SC Pickens	4.1	12.5	65.4	9.8	1,467.2	2	4
SC Spartanburg	4.4	11.8	63.0	13.1	633.5	2	3
TN Total	5.2	15.3	67.1	11.3	547.5		
TN App. Part	5.6	15.7	63.9	9.8	638.2		
TN Anderson	4.5	14.3	72.4	7.8	529.5	2	3
TN Bledsoe	4.7	19.2	52.1	11.3	3,233.3	8	3

continued

Selected Characteristics of Appalachia and Appalachian Counties (continued)

Summary Level	1990 Census Population	% Change Pop. 1970-1980	% Change Pop. 1980-1990	1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
TN Blount	86,000	22.3	10.5	14.7	7,690	15,304
TN Bradley	73,700	33.1	9.2	11.1	7,096	14,665
TN Campbell	35,100	34.2	0.6	14.7	5,496	10,912
TN Cannon	10,500	21.4	2.9	15.2	6,217	13,587
TN Carter	51,500	17.8	2.6	15.2	5,599	11,390
TN Claiborne	26,100	26.8	6.1	13.0	5,362	12,766
TN Clay	7,200	16.7	-6.5	16.3	4,756	12,031
TN Cocke	29,100	13.8	1.0	12.9	5,296	10,794
TN Coffee	40,300	17.8	5.2	14.0	7,701	15,518
TN Cumberland	34,700	38.6	20.9	17.6	5,407	12,420
TN DeKalb	14,400	22.5	5.9	15.8	6,484	13,018
TN Fentress	14,700	17.5	-0.7	13.4	4,141	9,617
TN Franklin	34,700	17.6	8.4	14.4	6,143	11,797
TN Grainger	17,100	20.0	1.8	12.9	5,022	10,504
TN Greene	55,900	14.5	2.8	13.8	6,246	13,017
TN Grundy	13,400	30.2	-2.9	14.3	4,681	11,020
TN Hamblen	50,500	27.4	2.4	12.0	6,352	13,779
TN Hamilton	285,500	13.1	-0.8	13.4	8,880	18,242
TN Hancock	6,700	3.0	-2.9	15.8	4,046	8,996
TN Hawkins	44,600	30.4	1.8	13.2	5,574	12,061
TN Jackson	9,300	16.0	-1.1	17.2	4,333	9,846
TN Jefferson	33,000	25.7	5.4	13.3	6,399	13,309
TN Johnson	13,800	18.1	0.7	16.4	5,793	9,901
TN Knox	335,700	15.7	5.0	12.7	8,446	17,382
TN Loudon	31,300	17.7	9.4	14.5	7,079	13,832
TN Macon	15,900	27.6	1.3	14.5	6,296	11,601
TN Marion	24,900	19.0	2.0	12.2	6,493	12,024
TN McMinn	42,400	18.4	1.2	14.3	6,463	13,455
TN Meigs	8,000	42.3	8.1	12.3	6,077	11,666
TN Monroe	30,500	22.1	6.3	13.7	5,014	11,772
TN Morgan	17,300	22.1	4.2	11.8	4,344	10,639
TN Overton	17,600	18.1	0.0	15.4	4,918	9,642
TN Pickett	4,500	18.9	2.3	17.2	3,970	8,645
TN Polk	13,600	17.2	0.0	14.4	6,137	10,979
TN Putnam	51,400	34.7	7.8	13.0	6,220	14,550
TN Rhea	24,300	41.5	0.4	14.3	7,455	13,841
TN Roane	47,200	24.4	-2.5	14.9	5,706	15,411
TN Scott	18,400	30.4	-4.7	12.0	5,054	11,119
TN Sequatchie	8,900	36.5	3.5	12.2	5,246	11,197

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate † 1984-1988	1990 Pop. per Patient-Care Doctor	1988 USDA‡, ♦ Rural/ Urban Code	ARC §, ♦ 1988 Distressed Counties
TN Blount	5.3	12.4	68.5	11.1	728.8	2	3
TN Bradley	4.7	13.8	64.4	10.2	809.9	4	3
TN Campbell	10.8	26.8	47.5	11.4	1,671.4	6	1
TN Cannon	7.7	14.5	54.6	5.0	1,500.0	8	2
TN Carter	4.9	18.0	57.5	9.2	1,661.3	2	2
TN Claiborne	6.3	25.7	50.8	12.1	2,175.0	6	2
TN Clay	4.0	23.0	48.5	2.6	1,440.0	9	3
TN Cocke	11.0	25.3	50.4	10.1	1,940.0	7	1
TN Coffee	5.3	15.2	65.1	10.8	857.4	5	3
TN Cumberland	7.7	18.1	59.8	9.8	867.5	7	1
TN DeKalb	6.1	20.3	50.3	6.8	1,600.0	6	3
TN Fentress	9.3	32.3	44.9	8.4	1,633.3	9	1
TN Franklin	4.9	14.4	63.5	8.4	1,388.0	7	2
TN Grainger	6.5	20.5	46.3	5.9	4,275.0	2	1
TN Greene	8.7	16.9	58.1	9.4	947.5	6	3
TN Grundy	9.1	23.9	44.7	8.1	4,466.7	8	1
TN Hamblen	6.0	13.9	61.6	8.4	952.8	6	2
TN Hamilton	4.2	13.1	72.5	11.1	400.4	2	3
TN Hancock	4.8	40.0	42.4	13.1	2,233.3	9	1
TN Hawkins	4.8	17.9	58.0	7.0	2,347.4	2	3
TN Jackson	6.8	20.0	45.2	6.6	1,860.0	9	1
TN Jefferson	6.8	15.1	60.5	3.5	1,833.3	2	2
TN Johnson	7.3	28.5	47.2	8.6	2,760.0	8	1
TN Knox	4.0	14.1	74.6	10.5	357.5	2	3
TN Loudon	5.1	13.6	63.8	5.8	1,360.9	6	3
TN Macon	7.3	19.3	49.2	12.7	2,650.0	6	2
TN Marion	7.0	19.3	51.9	9.6	1,778.6	2	1
TN McMinn	8.1	17.2	57.1	9.1	1,115.8	7	3
TN Meigs	9.4	22.3	52.7	14.5	8,000.0	8	3
TN Monroe	8.1	17.8	49.9	11.5	2,541.7	6	1
TN Morgan	8.9	20.2	56.7	7.1	8,650.0	8	1
TN Overton	9.2	17.9	44.1	8.9	2,514.3	7	1
TN Pickett	7.5	24.9	45.8	0.0	*	9	1
TN Polk	11.8	18.3	51.3	13.2	1,360.0	9	1
TN Putnam	5.4	16.6	63.2	8.7	815.9	5	3
TN Rhea	7.3	19.0	56.0	13.8	2,700.0	6	3
TN Roane	6.8	16.0	66.7	6.7	1,815.4	4	3
TN Scott	8.9	27.8	51.2	16.5	2,628.6	7	1
TN Sequatchie	5.4	22.9	51.4	0.0	2,966.7	2	2

continued

Selected Characteristics of Appalachia and Appalachian Counties (continued)

Summary Level	1990 Census Population	% Change Pop. 1970-1980	% Change Pop. 1980-1990	1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
TN Sevier	51,000	46.8	23.2	12.6	6,574	13,577
TN Smith	14,100	19.2	-5.4	15.9	5,828	14,726
TN Sullivan	143,600	13.0	-0.3	14.3	8,474	15,747
TN Unicoi	16,500	7.9	0.6	17.2	6,771	12,683
TN Union	13,700	28.6	17.1	11.0	5,066	9,843
TN VanBuren	4,800	27.0	2.1	12.3	3,919	9,753
TN Warren	33,000	21.1	0.9	14.5	7,847	13,222
TN Washington	92,300	20.2	3.9	14.0	7,515	15,982
TN White	20,100	15.3	2.6	16.1	5,339	12,777
VATotal	6,186,800	15.1	15.7	10.7	9,331	19,784
VA App. Part	517,800	17.2	-5.8	14.6	6,905	14,098
VA Alleghany	24,800	1.8	-12.7	18.1	7,783	14,521
VA Bath	4,800	13.5	-18.6	15.5	7,119	18,408
VA Bland	6,500	16.7	3.2	13.7	5,167	12,674
VA Botetourt	25,000	28.0	7.3	12.2	7,999	17,462
VA Buchanan	31,300	18.8	-17.6	8.7	7,650	13,944
VA Carroll	26,600	18.2	-2.6	16.0	5,290	12,664
VA Craig	4,400	11.4	12.8	14.0	6,682	13,297
VA Dickenson	17,600	23.8	-11.1	12.2	6,510	13,530
VA Floyd	12,000	18.4	3.4	16.6	5,545	14,618
VA Giles	16,400	6.6	-7.9	16.7	6,914	14,503
VA Grayson	22,900	6.9	-0.9	17.7	6,530	12,533
VA Highland	2,600	16.0	-10.3	19.6	6,456	12,883
VA Lee	24,500	28.1	-5.8	15.6	5,879	11,457
VA Pulaski	34,500	19.3	-2.0	14.7	6,636	13,386
VA Russell	28,700	29.8	-9.7	12.2	6,471	12,975
VA Scott	23,200	2.9	-7.6	16.7	5,841	12,024
VA Smyth	32,400	6.7	-3.0	15.1	5,975	14,316
VA Tazewell	46,000	27.2	-8.9	13.6	8,001	14,606
VA Washington	64,300	17.8	-1.8	15.5	6,840	15,265
VA Wise	43,800	21.8	-9.9	13.2	8,246	15,505
VA Wythe	25,500	15.4	0.0	15.4	6,637	13,770
WV Total	1,793,300	11.8	-8.0	15.0	7,669	13,719
WV App. Part	1,793,300	11.8	-8.0	15.0	7,669	13,719
WV Barbour	15,700	19.4	-5.4	16.0	6,727	9,735
WV Berkeley	59,300	28.9	26.7	11.8	7,565	13,345
WV Boone	25,900	21.1	-14.8	12.6	7,392	14,420
WV Braxton	13,000	9.4	-6.5	17.1	5,368	12,452

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate† 1984-1988	1990 Pop. per Patient-Care Doctor	1988 USDA‡, ♦ Rural/ Urban Code	ARC§, ♦ 1988 Distressed Counties
TN Sevier	9.4	13.2	63.0	8.8	2,040.0	2	3
TN Smith	6.7	14.5	54.2	6.8	1,566.7	6	3
TN Sullivan	3.6	13.6	66.8	9.3	403.4	2	3
TN Unicoi	7.4	17.1	59.6	10.3	2,062.5	2	3
TN Union	5.6	21.3	45.6	10.6	13,700.0	2	2
TN VanBuren	9.3	19.2	48.0	10.2	4,800.0	9	2
TN Warren	8.1	16.8	57.0	11.1	1,064.5	7	3
TN Washington	4.2	15.5	68.4	10.2	290.3	2	3
TN White	9.7	17.0	53.2	8.0	1,827.3	7	2
VA Total	4.3	9.9	75.2	11.0	534.5		
VA App. Part	7.4	17.3	56.4	9.5	988.2		
VA Alleghany	7.6	11.9	66.9	8.0	576.7	7	3
VA Bath	12.5	14.2	67.3	0.0	600.0	9	3
VA Bland	5.7	10.0	62.6	3.0	6,500.0	9	3
VA Botetourt	3.3	6.2	72.9	8.4	1,315.8	3	5
VA Buchanan	8.5	21.9	42.5	12.6	1,841.2	7	1
VA Carroll	6.5	14.1	49.7	10.0	633.3	7	3
VA Craig	5.8	9.8	68.4	0.0	4,400.0	8	3
VA Dickenson	13.7	25.9	47.1	12.2	2,933.3	9	2
VA Floyd	7.0	14.0	60.2	6.7	3,000.0	8	3
VA Giles	9.4	12.2	64.5	5.2	1,261.5	7	3
VA Grayson	8.2	16.3	52.5	11.0	4,580.0	7	3
VA Highland	6.2	13.6	61.8	6.3	1,300.0	9	3
VA Lee	8.3	28.7	48.0	10.2	1,531.3	9	1
VA Pulaski	9.7	13.4	59.6	9.7	1,277.8	7	3
VA Russell	9.1	22.5	50.6	10.9	2,207.7	6	3
VA Scott	5.5	20.9	51.2	9.2	4,640.0	2	3
VA Smyth	7.7	16.7	53.3	8.7	736.4	6	3
VA Tazewell	6.9	19.0	57.3	9.4	474.2	7	3
VA Washington	5.8	16.7	60.5	9.0	1,108.6	2	3
VA Wise	7.8	22.1	52.4	12.0	547.5	7	3
VA Wythe	7.7	17.5	61.8	7.3	1,108.7	7	3
WV Total	8.3	19.2	66.0	10.2	628.1		
WV App. Part	8.3	19.2	66.0	10.2	628.1		
WV Barbour	15.7	28.5	59.8	8.0	1,308.3	7	1
WV Berkeley	7.2	12.0	68.4	8.6	1,022.4	6	3
WV Boone	9.0	27.0	54.1	9.3	2,590.0	6	3
WV Braxton	11.9	25.8	56.8	7.5	2,166.7	9	1

continued

Selected Characteristics of Appalachia and Appalachian Counties (continued)

Summary Level	1990 Census Population	% Change Pop.		1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
		1970-1980	1980-1990			
WV Brooke	27,000	5.1	-13.2	16.4	8,401	13,424
WV Cabell	96,800	-0.2	-9.4	16.4	8,806	15,781
WV Calhoun	7,900	16.9	-4.8	15.7	5,254	8,952
WV Clay	10,000	21.5	-11.5	12.8	4,995	8,754
WV Doddridge	7,000	15.6	-5.4	16.2	5,166	9,948
WV Fayette	48,000	17.4	-17.1	17.1	6,715	11,334
WV Gilmer	7,700	7.8	-7.2	16.2	5,583	10,141
WV Grant	10,400	18.6	2.0	14.9	6,192	13,401
WV Greenbrier	34,700	17.4	-8.0	16.9	6,540	13,088
WV Hampshire	16,500	27.4	10.7	13.7	5,544	12,345
WV Hancock	35,200	1.5	-12.9	16.0	10,065	16,718
WV Hardy	11,000	13.6	10.0	15.3	5,686	13,483
WV Harrison	69,400	6.4	-10.7	17.7	7,989	14,463
WV Jackson	25,900	23.4	0.4	13.4	8,002	11,602
WV Jefferson	35,900	42.3	18.5	11.4	7,191	14,293
WV Kanawha	207,600	0.9	-10.3	15.7	9,858	17,192
WV Lewis	17,200	5.6	-8.5	16.5	6,544	11,644
WV Lincoln	21,400	25.4	-9.7	12.5	5,211	9,509
WV Logan	43,000	9.7	-15.2	12.6	7,479	13,245
WV Marion	57,200	7.2	-13.1	18.3	8,201	14,242
WV Marshall	37,400	10.9	-10.1	15.2	7,364	13,184
WV Mason	25,200	11.6	-6.7	14.1	6,890	12,166
WV McDowell	35,200	-1.4	-29.5	14.8	7,221	10,062
WV Mercer	65,000	16.9	-12.0	16.6	7,553	15,067
WV Mineral	26,700	17.7	-1.8	14.7	6,295	12,839
WV Mingo	33,700	13.7	-9.7	10.4	6,880	12,874
WV Monongalia	75,500	17.7	0.7	10.9	7,416	15,178
WV Monroe	12,400	15.2	-3.9	16.9	5,745	11,862
WV Morgan	12,100	25.9	13.1	16.9	6,031	13,180
WV Nicholas	26,800	24.9	-4.6	13.9	7,215	11,856
WV Ohio	50,900	-4.2	-17.1	18.9	9,233	18,181
WV Pendleton	8,100	12.9	2.5	17.2	4,770	10,762
WV Pleasants	7,500	12.3	-8.5	14.6	7,674	13,081
WV Pocahontas	9,000	12.5	-9.1	18.9	5,537	12,849
WV Preston	29,000	19.6	-4.9	14.0	6,448	10,234
WV Putnam	42,800	38.4	12.0	11.0	7,610	13,831
WV Raleigh	76,800	23.8	-11.5	15.3	7,763	13,267
WV Randolph	27,800	16.7	-3.1	15.8	6,677	12,302
WV Ritchie	10,200	11.8	-10.5	17.4	5,987	11,218

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate † 1984-1988	1990 Pop. per Patient-Care Doctor	1988 USDA‡, ♦ Rural/ Urban Code	ARC §, ♦ 1988 Distressed Counties
WV Brooke	7.2	12.1	71.6	13.4	2,700.0	3	3
WV Cabell	6.2	19.1	71.9	10.5	296.9	2	3
WV Calhoun	17.5	32.0	56.3	11.6	1,128.6	9	1
WV Clay	14.5	39.2	49.4	7.4	5,000.0	8	1
WV Doddridge	8.6	23.0	64.6	8.0	2,333.3	9	1
WV Fayette	10.7	24.4	57.1	8.0	1,090.9	6	2
WV Gilmer	8.7	33.5	56.6	17.7	7,700.0	9	1
WV Grant	8.8	15.5	60.2	8.0	800.0	9	1
WV Greenbrier	11.0	17.9	63.0	6.4	680.4	7	3
WV Hampshire	11.4	18.2	61.8	6.0	2,750.0	8	2
WV Hancock	6.4	11.9	72.5	6.7	748.9	3	3
WV Hardy	6.1	14.6	55.3	6.5	5,500.0	9	2
WV Harrison	8.8	17.4	70.6	13.7	568.9	5	3
WV Jackson	10.9	20.0	65.4	8.0	1,850.0	6	3
WV Jefferson	5.4	10.6	68.2	12.7	1,495.8	6	3
WV Kanawha	6.0	15.3	72.4	8.6	386.6	2	3
WV Lewis	10.7	23.7	62.1	14.4	1,146.7	7	2
WV Lincoln	12.7	33.8	49.1	12.0	5,350.0	8	1
WV Logan	11.1	27.7	53.4	7.6	754.4	7	2
WV Marion	8.6	19.0	71.4	11.7	969.5	5	3
WV Marshall	7.9	16.0	70.9	6.4	1,335.7	3	3
WV Mason	9.6	22.1	61.1	12.4	1,008.0	6	3
WV McDowell	15.7	37.7	42.3	13.5	1,760.0	7	1
WV Mercer	8.0	20.4	63.1	13.3	503.9	5	3
WV Mineral	5.5	14.8	72.8	10.0	2,053.8	3	3
WV Mingo	9.3	30.9	50.4	13.6	962.9	7	1
WV Monongalia	3.7	20.6	75.4	9.1	170.0	5	3
WV Monroe	7.1	21.0	62.1	15.3	1,771.4	9	2
WV Morgan	6.6	11.0	64.8	9.4	2,016.7	8	3
WV Nicholas	13.8	24.4	61.2	10.5	1,488.9	7	2
WV Ohio	5.2	15.0	75.1	12.4	217.5	3	3
WV Pendleton	5.2	17.0	60.6	12.5	2,025.0	9	3
WV Pleasants	13.1	19.4	68.7	16.1	1,071.4	8	3
WV Pocahontas	12.3	21.2	60.6	8.7	4,500.0	9	3
WV Preston	8.1	18.9	62.7	14.3	1,526.3	7	1
WV Putnam	7.9	12.0	73.8	9.2	1,945.5	2	3
WV Raleigh	9.1	19.9	63.2	8.1	486.1	5	3
WV Randolph	14.2	21.9	65.9	13.7	695.0	7	2
WV Ritchie	12.4	26.0	61.5	11.4	10,200.0	8	2

continued

Selected Characteristics of Appalachia and Appalachian Counties (continued)

Summary Level	1990 Census Population	% Change Pop.		1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
		1970-1980	1980-1990			
WV Roane	15,100	13.5	-5.6	15.5	5,823	9,944
WV Summers	14,200	20.5	-10.7	17.5	5,670	9,091
WV Taylor	15,100	19.4	-9.0	16.2	6,020	10,182
WV Tucker	7,700	17.6	-11.5	16.8	5,623	12,036
WV Tyler	9,800	14.1	-13.3	15.4	6,601	12,749
WV Upshur	22,900	23.2	-2.1	14.7	6,835	10,743
WV Wayne	41,600	22.3	-9.6	13.7	6,560	11,840
WV Webster	10,700	24.5	-12.3	15.5	4,919	9,608
WV Wetzel	19,300	7.9	-11.9	14.8	7,789	13,494
WV Wirt	5,200	19.5	6.1	14.3	6,419	8,421
WV Wood	86,900	8.0	-7.2	14.8	8,673	15,618
WV Wyoming	29,000	19.6	-19.4	10.9	6,460	10,159

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate† 1984-1988	1990 Pop. per Patient-Care Doctor	1988 USDA‡, ♦ Rural/ Urban Code	ARC §, ♦ 1988 Distressed Counties
WV Roane	16.1	28.1	57.2	9.3	1,372.7	6	2
WV Summers	11.0	24.5	58.0	6.6	1,290.9	7	1
WV Taylor	10.4	22.9	66.0	5.9	3,020.0	7	3
WV Tucker	11.4	17.0	64.0	11.4	1,100.0	9	2
WV Tyler	8.7	18.3	68.7	6.3	4,900.0	9	3
WV Upshur	11.4	21.2	64.3	8.2	954.2	7	2
WV Wayne	8.4	21.8	63.1	8.9	6,933.3	2	1
WV Webster	19.2	34.8	46.5	13.4	2,675.0	9	1
WV Wetzel	9.1	20.5	70.1	9.5	1,484.6	6	3
WV Wirt	15.4	22.0	66.2	10.8	*	8	2
WV Wood	7.4	14.1	73.2	10.9	730.3	3	3
WV Wyoming	12.9	27.9	53.0	10.9	2,636.4	7	1

*No patient care doctor in county.

†Number of infant deaths per 1,000 live births. This 5-year infant mortality rate was computed: sum of infant deaths (1984-1988)/sum of live births (1984-1988) x 1,000. An infant death is defined as the death of a child less than one year old.

‡See Appendix F for definitions of USDA Rural/Urban Continuum Codes.

§Distressed county ranks: 1 = severely distressed, 2 = distressed, 3 = middle, 4 = strong, and 5 = very strong.

♦County ranks do not apply to state totals or areas other than single counties.

Source: Rural Health Research Program, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, NC.

Data Source: Health Resources and Services Administration, September 1993 Area Resource File, with additional information on the economic status of Appalachian counties from the Appalachian Regional Commission, "Distressed County Data for Appalachian Counties," August 25, 1992.

Appendix B

*Selected Characteristics of Urban and Rural Appalachian Counties**

Summary Level	1990 Census Population	% Change Pop. 1970-1980	% Change Pop. 1980-1990	1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
Total United States	248,799,500	11.5	9.8	12.6	9,526	18,746
Urban United States	212,221,300	11.0	11.1	12.1	9,955	19,538
Rural United States	36,578,200	14.2	2.7	15.3	7,224	14,154
Total Appalachia	20,701,400	11.1	1.6	14.3	7,790	15,331
Urban Appalachia	14,094,800	8.6	1.8	14.3	8,374	16,387
Urban Northern	7,634,000	1.8	-3.9	16.0	8,726	16,383
Urban Central	483,900	18.1	-3.6	14.1	7,614	14,332
Urban Southern	5,976,900	19.4	10.8	12.2	7,925	16,558
Rural Appalachia	6,606,600	17.0	1.3	14.3	6,552	13,077
Rural Northern	2,283,800	12.6	-0.3	14.9	7,012	13,510
Rural Central	1,531,300	22.5	-5.1	13.1	6,071	11,677
Rural Southern	2,791,500	17.7	6.5	14.4	6,446	13,491
AL App. Part	2,529,600	13.8	4.1	13.0	7,696	15,636
AL Urban	2,023,200	13.0	4.3	12.7	8,076	16,288
AL Rural	506,400	17.0	3.3	14.4	6,191	13,029
GA App. Part	1,508,000	35.8	36.6	9.7	7,127	16,420
GA Urban	948,400	47.7	47.5	8.1	7,342	17,619
GA Rural	559,600	22.1	21.4	12.3	6,827	14,389
KY App. 3Part	1,045,300	23.1	-2.9	12.5	6,086	11,759
KY Urban	199,200	17.1	-1.1	12.4	7,428	14,029
KY Rural	846,100	24.6	-3.4	12.6	5,777	11,225
MD App. Part	224,400	5.2	2.0	15.4	7,824	15,405
MD Urban	196,300	3.1	1.4	15.6	8,024	15,717
MD Rural	28,100	23.8	6.0	13.8	6,363	13,226
MS App. Part	510,600	15.0	2.5	13.3	6,241	12,241
MS Urban	124,900	19.5	9.2	10.9	7,559	14,358
MS Rural	385,700	13.7	0.5	14.1	5,848	11,555
NY App. Part	1,088,600	2.5	0.5	14.0	7,921	15,383
NY Urban	828,000	0.9	-0.1	13.9	8,226	15,758
NY Rural	260,600	8.2	2.5	14.6	6,929	14,195

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate† 1984-1988	1990 Pop. per Patient-Care Doctor
Total United States	5.5	12.8	75.2	10.4	516.4
Urban United States	5.4	12.1	76.6	10.4	467.2
Rural United States	6.6	17.0	67.1	10.3	1,330.0
Total Appalachia	6.2	14.8	68.4	10.4	680.8
Urban Appalachia	5.6	13.0	72.2	10.3	572.1
Urban Northern	5.9	12.9	74.7	9.7	566.4
Urban Central	6.6	18.1	64.4	9.8	683.5
Urban Southern	5.1	12.7	69.7	11.1	572.0
Rural Appalachia	7.6	18.7	60.0	10.6	1,144.6
Rural Northern	8.2	16.0	68.5	9.4	967.7
Rural Central	8.4	27.6	49.7	11.1	1,257.2
Rural Southern	6.9	16.1	58.5	11.4	1,272.3
AL App. Part	6.5	15.5	67.1	12.2	625.5
AL Urban	6.1	14.9	70.0	12.0	535.0
AL Rural	8.1	17.7	55.5	13.0	1,932.8
GA App. Part	5.6	9.8	67.5	10.2	1,242.2
GA Urban	5.0	7.9	72.9	9.4	1,254.5
GA Rural	6.6	13.1	58.5	11.6	1,221.8
KY App. Part	7.7	28.4	51.5	11.2	1,183.8
KY Urban	6.6	18.6	64.3	10.2	889.3
KY Rural	8.0	30.7	48.4	11.4	1,283.9
MD App. Part	7.6	11.8	69.7	9.8	688.3
MD Urban	7.4	11.4	69.9	9.1	645.7
MD Rural	8.9	14.4	68.4	14.4	1,277.3
MS App. Part	8.2	22.0	59.3	12.8	1,179.2
MS Urban	6.4	18.2	68.4	12.8	589.2
MS Rural	8.8	23.2	56.3	12.7	1,745.2
NY App. Part	4.7	12.2	77.3	9.3	697.4
NY Urban	4.5	12.2	77.8	9.4	686.0
NY Rural	5.2	12.1	75.6	9.0	736.2

continued

*Selected Characteristics of Urban and Rural Appalachian Counties**

Summary Level	1990 Census Population	% Change Pop. 1970-1980	% Change Pop. 1980-1990	1990 % Pop. 65 and Over	1980 Per Capita Income $	1990 Per Capita Income $
NC App. Part	1,306,700	17.4	7.3	14.9	7,596	16,165
NC Urban	639,500	16.2	8.7	13.5	8,440	18,049
NC Rural	667,200	18.6	6.0	16.2	6,807	14,358
OH App. Part	1,372,800	11.3	-0.2	13.7	7,542	13,442
OH Urban	935,800	9.2	-0.8	13.6	7,890	14,001
OH Rural	437,000	16.2	1.1	13.9	6,783	12,245
PA App. Part	5,769,400	1.1	-3.8	16.7	8,759	16,775
PA Urban	4,818,900	-0.1	-4.4	16.9	9,014	17,151
PA Rural	950,500	8.3	-0.1	15.6	7,407	14,871
SC App. Part	888,100	20.7	12.1	12.5	7,916	16,179
SC Urban	786,100	21.4	11.9	12.3	8,016	16,291
SC Rural	102,000	15.6	13.8	13.4	7,132	15,315
TN App. Part	2,146,800	19.7	3.5	13.7	7,215	14,757
TN Urban	1,485,200	18.6	3.7	13.5	7,828	15,898
TN Rural	661,600	22.4	3.0	14.3	5,849	12,196
VA App. Part	517,800	17.2	-5.8	14.6	6,905	14,098
VA Urban	112,500	16.0	-1.2	15.0	6,880	15,083
VA Rural	405,300	17.5	-7.0	14.4	6,911	13,825
WV App. Part	1,793,300	11.8	-8.0	15.0	7,669	13,719
WV Urban	996,800	8.2	-9.1	15.5	8,467	15,228
WV Rural	796,500	16.9	-6.6	14.4	6,642	11,830

Summary Level	1990 % Workforce Unemployed	1989 % Pop. Below Poverty	1990 % Pop. 25 and Over with H.S. Diploma	5-Year Infant Mortality Rate† 1984-1988	1990 Pop. per Patient-Care Doctor
NC App. Part	4.3	12.1	67.1	10.8	557.9
NC Urban	3.8	10.3	71.8	10.9	386.2
NC Rural	4.7	13.8	62.5	10.7	972.6
OH App. Part	7.0	16.9	69.2	9.4	1,357.9
OH Urban	6.4	15.8	71.1	9.3	1,246.1
OH Rural	8.4	19.3	65.0	9.4	1,680.8
PA App. Part	6.2	12.1	75.0	9.6	548.6
PA Urban	5.9	12.0	75.5	9.7	521.0
PA Rural	7.7	12.7	72.1	8.9	749.6
SC App. Part	4.3	11.2	66.3	12.7	666.2
SC Urban	4.2	11.0	67.0	12.8	636.5
SC Rural	5.4	12.8	60.8	12.4	1,040.8
TN App. Part	5.6	15.7	63.9	9.8	638.2
TN Urban	4.7	14.2	68.1	9.8	508.1
TN Rural	7.7	19.2	54.3	9.7	1,500.2
VA App. Part	7.4	17.3	56.4	9.5	988.2
VA Urban	5.1	14.8	61.3	8.9	1,372.0
VA Rural	8.1	18.0	55.0	9.6	917.0
WV App. Part	8.3	19.2	66.0	10.2	628.1
WV Urban	6.8	16.5	70.9	10.1	442.2
WV Rural	10.4	22.6	59.7	10.3	1,325.3

*See Appendix F for definition of urban and rural counties.

†Number of infant deaths per 1,000 infant births. This 5-year infant mortality rate was computed: sum of infant deaths (1984-1988)/sum of live births (1984-1988) x 1,000. An infant death is defined as the death of a child less than one year old.

Source: Rural Health Research Program, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, North Carolina.

Data Source: Health Resources and Services Administration, September 1993 Area Resource File, with additional information on the economic status of Appalachian counties from the Appalachian Regional Commission, "Distressed County Data for Appalachian Counties," August 25, 1992.

Appendix C

Monograph Development and Program Implementation

Richard A. Couto

This monograph developed as an integral part of the Appalachia Leadership Initiative on Cancer (ALIC) program, rather than as separate research, and as a means of improving the prospects of ALIC's successful implementation. The editors intended the monograph as a step from the National Cancer Institute's (NCI) concept paper for the ALIC program and the original project proposals to the planning and initial implementation of the ALIC projects. This appendix recounts the efforts to meld the evolution of the monograph with the planning and implementation of ALIC.

Purpose

Despite the rapid growth of policy "think tanks" and the increasing attention to public policy in the past 20 years, one central issue remains troubling for policy analysts: The intended outcomes of public policies and programs often are not achieved. In *Implementation: How Great Expectations in Washington Are Dashed in Oakland; or Why It's Amazing That Federal Programs Work at All...*, the authors explain the gap between policy intentions and program outcomes in terms of implementation. They describe implementation as actions that start with initial conditions and infer a causal chain that links actions to change among those initial conditions. The longer the chain of causality, the more complex the linkages in the chain and implementation (Pressman and Wildavsky 1973).

In the 20 years since Pressman and Wildavsky's study, implementation and its complexity have received even more attention. One analyst has characterized implementation as the missing link in policy analysis (Hargrove 1976). Others have identified the ramifications of using different actors to implement public programs (Chase 1979; Salamon 1981). There is now much more information on processes, institutional roles, and actions that are relevant to implementation, but still missing are the linkages between these elements of a program and outcomes (Salamon 1989).

To ensure that this monograph fulfilled our "great expectations," the contributors identified program components and developed the monograph around them. Also involved in the monograph's development were the people responsible for implementing ALIC. Finally, we facilitated discussion among the contributors, projects' staffs, NCI staff, and editors to achieve a synergism of ideas and opinions. These methods flow directly from several critiques of the role of social science in social problemsolving as well as from concerns about program implementation. These critiques support and suggest alternative methodologies such as action research and participatory research (Argyris et al. 1985; Lincoln and Guba 1985;

Lindbloom 1990; Lindbloom and Cohen 1979; Couto 1987), which has a rich history in the Appalachian region. The methods of the Highlander Center have institutionalized participatory research (Horton and Freire 1990; Glenn 1988) and continue it (Merrifield 1989; Beaver 1983; Greider 1992). As editors, we attempted to combine the scattered information of numerous professionals and academic researchers with the practical task of project staff to achieve the goals and objectives of ALIC. At the very least, these methods are intended to ensure the relevancy of this monograph to the program. At most, they improve the monograph and the program by engaging those responsible for each part in discussion with each other.

The monograph had a fast-track timeframe for development. The first work session was held May 13, 1992; initial planning concluded at the end of the summer, just before the four ALIC project awards were made; and the monograph was published in September 1994. The early projection for monograph completion by July 1993 proved to be too ambitious. We took the additional time to develop the potential of a monograph that evolved in discussion to exceed our initial expectations.

For this monograph to serve as an integral part of ALIC and not just as an isolated publication effort, we envisioned it as a useful tool for project staff that also could be easily marketed by the program director in Washington to project implementors. We wanted a monograph that the project staff could use to explain ALIC to coalition members, key decision makers, media representatives, and other actors in the program. To be useful, the monograph had to provide them with valuable information on Appalachia, its health care needs, and the principles of good practice in ALIC's program features. Thus, the monograph's primary purpose is seen as the provision of background material to prospective coalition members within the ALIC-funded projects to make them better informed and more effective participants and leaders, with special emphasis on information on the chain of causality from cancer incidence and risk to cancer prevention and control through community-based interventions in Appalachia. The monograph also is intended to serve as common ground whereby project coalition members with diverse perspectives can discuss their differences about the vital elements of ALIC in a common language.

To ensure its utility, the monograph's development became part of the first-year planning of each ALIC project. By asking representatives of each project to develop a portion of the monograph, the editors created a transition from the project's proposal to planning in the first program year. Staff members from each project also participated in discussing all aspects of the monograph and each draft of all the chapters. In designing this monograph to deal with ALIC in a prospective manner, the editors hoped to establish a baseline that would lay the groundwork for a revision and an additional, retrospective monograph after five years of program experience. To serve as a baseline, the monograph would have to incorporate the most recent research on pertinent topics. The 5-year retrospective version would then more effectively illustrate lessons learned from the ALIC program.

This monograph also has a broader purpose—to illustrate a process that unites monograph development and program-related research to program planning, implementation, and evaluation. Although the monograph deals with Appalachia and cancer, its content and development process illustrate generic lessons for other policies and programs, regardless of region and issue.

Methods

Initially, the editors proposed several steps for integrating the monograph into the ALIC program.

► Use material from the ALIC projects' applications in chapters of the monograph.

► Use project staff members as contributors to the monograph and as reviewers of the work of other contributors, editors, and peer reviewers via day-long work sessions.

► Plan and write the monograph during the planning year of the projects to inform the planning process of all the projects and to ensure that monograph development became part of each project's first year of activity.

► Assemble state-of-the-art information relevant to the multiple facets of the ALIC projects so that the monograph could serve as a baseline for ALIC and a prospective statement of the need, the program, and its prospects and problems.

To accomplish these steps in the available time, we identified the following criteria in a morning work session on May 13, 1992:

► Include the NCI concept paper that explained the program and its background to ALIC.

► Ensure that the monograph has an immediate link to the ALIC projects by revising portions of the successful applications and incorporating them as chapters describing the individual ALIC projects.

► Include the best and most current information on community-based health interventions. This included several other NCI coalition efforts that had not yet been compared and analyzed and other NCI leadership initiatives.

► Identify principles of effective practice germane to ALIC.

► Review specific organizing and coalition efforts that involved residents of Appalachia and cancer patients.

► Establish other relevant contexts and resources for ALIC, including other health promotion efforts such as the *Healthy People 2000* program (U.S. Department of Health and Human Services 1991).

► Report lessons already learned about the links between cancer and socioeconomic status.

► Portray a complex and dynamic region in terms of its political economy, health care needs and services, and community organizing and citizens' efforts.

► Incorporate the key institutional actors for implementing this program (including the Appalachian Regional Commission, foundations, and various NCI branches) and develop roles for them to play in preparing this monograph.

We distributed information about the task and brought together all the contributors and key players at meetings with project staff (as soon as the four ALIC awards were made). Our assemblage included some people who knew a lot about Appalachia, some who knew a lot about NCI, some who approached cancer from a social science viewpoint and some from a medical science viewpoint, and others with a variety of often-conflicting perspectives. This diversity supplied a vital mix that we hoped we could contain within the covers of the monograph. Our monograph discussions provided an energetic exchange of perspectives and stimulated contributors to respond to diverse views and to the need of the projects for relevance.

Activities

At the first meeting on October 29, 1992, participants discussed the monograph outline and the contributors' chapter outlines and drafts. This meeting shaped the direction of each chapter and the range of its discussion by giving each contributor an idea of the rough fit of the individual chapter within the monograph. By this time, plans for the monograph had changed considerably. Some intended contributors were unwilling or unable to work on the monograph. We had to seek out other contributors who were at an initial disadvantage because they were invited to participate too late to prepare and submit material for the meeting. Nonetheless, a reasonable facsimile of the intended monograph outline emerged from the October meeting.

The anticipated different perspectives of the participants ensured a vigorous exchange and led to an examination of conflicting expectations for the monograph. Time and budgetary restraints limited what could be established. With insufficient time to generate new hard evidence for prevention strategies in Appalachia, we determined to conduct special computer analyses of previously unreported data that were easily available, report data we could find or generate easily, and report some data that were not readily available only if they were absolutely necessary for the projects. We decided not to produce a how-to book on creating community-based, cancer prevention and control coalitions; instead, we accommodated this need by adding Appendix D, Resources.

The October meeting stimulated reactions to approaches to change in the Appalachian region. Contributors and project staffs contrasted change efforts initiated by public agencies and university-related programs with those initiated by local residents in response to their articulated and perceived needs. A recurring example of this contrast was the gap between the plethora of grassroots organizing efforts around environmental issues and the lack of official action because epidemiological evidence was insufficient to proceed in a cancer prevention and control program. This gap was symptomatic of a tension within the group that combined federal agency staff, institutional agents, and academic researchers. Each group member had a different stream of information and line of accountability. Some were or felt accountable, in different degrees, to NCI, other federal agencies, breast cancer coalitions, organized groups in Appalachia, academic disciplines, medical care innovators, host institutions, and many others.

Without resolving all differences, participants in the October meeting found common ground on which to proceed. The monograph would deal with cancer prevention and control, empowerment, culture and its role in Appalachian change efforts, and a set of institutional actors within Appalachia. Contributors agreed to express ideas in a common language, identify differences, and acknowledge areas where important information was lacking.

At the second meeting, on March 1, 1993, most members of the first group met again to discuss second drafts, revisions, and work based on the first meeting. The problems with the initial plans for the monograph were apparent, but so were the prospects. Additional attendees included peer reviewers to provide initial assessments and criticisms of the work. The second meeting also allowed the project staff to speak to the contributors about the usefulness and relevance of their work to date. Some elements of the original outline had not developed well because the research to compile, report, and apply them to ALIC was lacking. Other parts of the monograph had developed so well that the chapters seemed bursting at the seams. As with all collaborative works, a consistent tone proved elusive, and themes differed from chapter to chapter. Unlike other volumes, however, this monograph had a forum for contributors and project staffs to engage one another about their differences. In addition, we invited to our March meeting discussants who had expertise in one or more areas covered in the monograph. We also invited staff and directors of health agencies within NCI and the U.S. Department of Health and Human Services. Their encouragement influenced the subsequent development of the monograph. For example, William Robinson, chief medical officer of the Health Resources and Services Administration, assured the group that

> *Congress is interested in programs such as ALIC.... ALIC will be examined to determine whether people will participate in community-based coalitions and whether federal dollars and local initiatives can provide any kind of leadership to improve cancer control.... Coalition-building efforts should expect to*

advance by a series of little steps and to encounter negativism because people often do not want to give of themselves for the benefit of the coalition. But these difficulties are a part of the process and must be worked through in each community. We also need to recognize that every community is different, and what works in one county may not work in another county.

The March meeting was difficult but rewarding. The more developed the monograph became, the more its possibilities and limits became evident, and the more persistently unanswered questions demanded answers. For example, who was the intended audience? Some chapters initially spoke to the ALIC project staffs with a list of do's and don'ts. This was a limited audience, for whom a memo would have been a better communication tool than a book chapter. Some chapters spoke to colleagues in NCI in terms mainly familiar to the federal government community. Some project chapters still read like proposals trying to sell funders on the virtues of particular grantees.

The March meeting reshaped the monograph. The project staffs wanted chapters that better reflected their plans midway in program year 1, rather than their proposals' projections. We were told that we could no longer evade the issue of culture and its role in change in the region. Our tone was too academic for the most part and lacked "heart." Some chapters split and became two. The order of the chapters changed to organize the sections and the entire monograph more clearly. We had to decide between setting time limits for the adequate development of some chapters or giving up on them. Individual contributors left with direct messages from other contributors and representatives of their intended audiences. This made the editors' task one of reinforcing what had been said as well as communicating our own decisions.

As clear as our differences were at the March meeting, it also was clear that we were reaching for something we now thought attainable that had not seemed so four months earlier. We had a better and clearer sense of producing something of value to the project, and we developed stakes in doing it right. This sense of importance, reinforced by our interaction at that meeting, assisted us in dealing with the details and problems of doing what had to be done. We grouped together people who knew a lot about different aspects of ALIC and encouraged them to talk. This gave contributors graphic impressions of reactions to their work, questions, challenges, and insights. We conveyed the goals for the monograph and created common elements for it—for example, an intended audience. We also reconciled different accountability patterns among intended participants within ALIC, NCI, and NCI watchers—Congress, cancer researchers, and cancer voluntary organizations. In the process, the monograph assumed a common tone from chapter to chapter. Contributors spoke from the data about community-based interventions and to our target audience, epitomized as an editor of a weekly local newspaper in rural Appalachia. This was a change from contributors speaking to each other about their own perceptions of the others' positions.

Perhaps the decision on the monograph's intended audience had the most impact for the monograph as part of ALIC. We understood that there would be three audiences for this monograph: those whom ALIC hoped to incorporate into its projects as coalition members, legislators and local officials, and other informed lay people with influence to shape public opinion; watchers of NCI in the federal bureaucracy, Congress, and academic medicine centers; and officials and staff members of the various branches, divisions, and offices within NCI. We chose to write for the first audience primarily. We did not abandon the perspective of those within or associated with the federal government; we hoped to broaden it. We hoped to show what a group of people could do with the trust and support of a federal agency. We determined that the test of what

we did would be left to the people intended as participants in the ALIC projects. We trusted the people of the other two audiences to measure our success not by how we conformed to what had been done before but by how well we met the needs of the people who would carry out ALIC.

Involving so many people directly created a tension between wanting to incorporate new facets into the monograph and keeping monograph development within a set of manageable tasks that could be completed in the timeframe we had established. The forms of collaboration and exchange that we created delayed some aspects of the work. The delay was fortuitous because that collaboration and exchange improved the work. Our methods did not substitute for hard work. In particular, working with the project staffs to create monograph chapters from sections of proposals proved more difficult than we had anticipated. As proposals turned into programs, the task grew more difficult because projects modified portions of their proposed plans. In a sense, we invited this difficulty by creating forums for the exchange of ideas about programs as part of the monograph development. In addition, ALIC project staffs had other forums for exchanging ideas among themselves. This process meant that we were trying to capture in print an evolving project and to convey a sense of the intent of the projects before they could commit to specific elements of a plan.

Conclusion

In retrospect, our intended goal of action research and collaboration in monograph development resembled the intent of ALIC for its projects. Not surprisingly, therefore, we replicated some of the benefits and pitfalls of coalition efforts in the development of this monograph. In our discussions, in particular, we became aware of disparate perspectives that almost destroyed the possibility of group cohesion. Some people pushed at institutional boundaries and the boundaries of health care change from inside institutions. Other participants pulled at those boundaries from various positions within the community but outside of medical care institutions. Although everyone wanted movement, and most often in the same direction, where people stood and whether they pushed or pulled for change influenced how they responded to the analysis of the problems and to the generalizations about institutional medical care providers or community groups and coalitions. Our discussions, probably like those that will occur within the coalitions of the ALIC projects, would have proceeded more quickly and with more harmony if we had had fewer perspectives assembled for those discussions. We chose to move more slowly along a broader front, including untraveled paths, rather than to move quickly along narrower, more traveled paths.

Proceeding in this way takes time, commitment, and facilitation skills. Trust and leadership play essential roles. Leadership mobilizes or develops a group's resources to pursue a shared vision of improvement. A large part of leadership involves creating trust among group members about the capacity and relevance of each member to the group's goals. On more than one occasion, the group recognized that we were not only developing a monograph for the ALIC projects but also dealing with their problems as well as their promise. The lessons learned from this process have been stated in the Conclusion of the monograph.

Inevitably, we did not accomplish everything that we thought could be accomplished with this monograph, but we exceeded the pattern and expectations with which we started. We hope that, with the same tensions, the equivalent amount of talent and hard work, and a degree of cooperation and collaboration equal to what we had on the monograph, we will be able to say the same about ALIC in five years. It may not achieve everything it might

have, but it exceeds what had been done before and presents new possibilities for others to achieve and surpass.

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Appendix D

Resource Section

This appendix lists selected agencies and other organizations that can be valuable resources to members of community-based coalitions and other participants in the Appalachia Leadership Initiative on Cancer (ALIC). These groups may be able to provide useful information, materials, services, or linkages to other potential resources. The section is divided into five topic areas:

1. ALIC programs,
2. Appalachia,
3. Cancer,
4. Rural health,
5. Coalitions, community development, and health education.

Within each area, relevant federal, state, and private-sector resources are identified.

Space does not permit listing all local organizations that deal with the broad range of issues pertaining to these topic areas. However, for several organizations, a central office is given that can provide referrals to local constituent member groups or chapters in the Appalachian region.

The phone numbers and addresses for some of the organizations listed in this resource section may have changed since the monograph was prepared. If more current information is needed, contact the ALIC Program Director's office or one of the ALIC projects listed below.

1. Appalachian Leadership Initiative on Cancer

Appalachia Leadership Initiative on Cancer Program
ALIC Program Director
National Cancer Institute
9000 Rockville Pike, EPN 233
Rockville, Maryland 20892
(301) 496-8584

The Appalachia Leadership Initiative on Cancer (ALIC) is the National Cancer Institute's formal outreach initiative to increase cancer prevention and control activities in the Appalachian Region. ALIC supports the following four subregional projects:

Northern Appalachia Leadership Initiative on Cancer (NALIC)
NALIC Principal Investigator
Department of Food Science/Borland Laboratory
Pennsylvania State University
University Park, Pennsylvania 16802
(814) 863-4751

The NALIC project serves the Appalachian portions of New York, Pennsylvania, and Maryland.

North Central Appalachia Leadership Initiative on Cancer (NCALIC)
NCALIC Principal Investigator
Mary Babb Randolph Cancer Center
Health Sciences Center
West Virginia University
P.O. Box 9300
Morgantown, WV 26506-9300
(304) 293-3528

The NCALIC project serves all of West Virginia and the Appalachian portions of Ohio.

Central Highlands Appalachia Leadership Initiative on Cancer (CHALIC)
CHALIC Principal Investigator
Markey Cancer Center
University of Kentucky Medical Center
206 Davis-Mills Building, MRISC
800 Rose Street
Lexington, Kentucky 40536-0098
(606) 257-5323

The CHALIC project serves the Appalachian portions of Kentucky, Tennessee, and Virginia.

Southern Appalachia Leadership Initiative on Cancer (SALIC)
SALIC Principal Investigator
North Carolina Cooperative Extension Service
North Carolina State University
Box 7605
Raleigh, NC 27695-7605

The SALIC project serves the Appalachian portions of North Carolina, South Carolina, and Georgia.

2. Appalachia

Federal Resources

Appalachian Regional Commission
1666 Connecticut Avenue, N.W.
Washington, D.C. 20235
(202) 673-7968

The Appalachian Regional Commission (ARC) was established by Congress in 1965 to assist in the long-term development of the region. ARC undertakes projects in two areas. The highway program provides for the construction of the Appalachian Development Highway System to support industry and tourism and to enable the region's residents to move freely between home and work, school, and other public facilities. The other program area undertakes projects to address two goals: (1) creation of new jobs and private investments and (2) special help for the region's poorest or "distressed" counties. ARC provides grants to support education, health care, water and sewer services for industrial and commercial needs, housing, small business development, development of natural resources, and research on topics directly related to Appalachia's economic development.

ARC's organizational structure is designed to ensure the federal, state, and local cooperation needed to achieve ARC objectives. The commission has 14 members: the governors of the 13 Appalachian states and a federal cochair who is appointed by the President. To ensure a partnership with local participants, ARC, through its member states, works with multicounty planning and development agencies known as local development districts (LDDs). In turn, LDDs work with local citizens to determine local needs and priorities and to prepare and implement development plans based on those needs and priorities. ARC also publishes *Appalachia*, a quarterly journal.

State Resources

Berea College
Appalachian Center
Appalachia Museum
Brushy Fork Institute
College Box 2336
Berea, Kentucky 40404
(606) 986-9341 (main campus); ext. 5140 (Appalachian Center); ext. 6838 (Brushy Fork); ext. 6078 (Appalachia Museum)

Berea College's resources pertaining to Appalachia include the Appalachia Center, the Appalachia Museum, and the Brushy Fork Institute, relocated to the Appalachian Museum, and the Weatherford-Hammond Mountain Collection. The Brushy Fork Institute offers training and support to both emerging and established community leaders in a four-state area that includes Kentucky, Tennessee, Virginia, and West Virginia. The institute's Leadership Development Program offers workshops to diverse teams of community leaders. The Student Leadership Development Program helps students develop skills and perspectives that can be used in future public service. The Brushy Fork Institute also publishes two newsletters: *Across the Ridge* and *Mountain Promise*. Berea College also sponsors a variety of projects, including the W.D. Weatherford Award, which presents $500 to a "writer whose work best illustrates the problems, personalities, and unique qualities of the Appalachian South." The college's Appalachian Center sponsors Students for Appalachia, a group that implements outreach projects.

East Tennessee State University
Center for Appalachian Studies and Services
Box 70556
Johnson City, Tennessee 37614-0556
(615) 929-5348

Established in 1984, the Center for Appalachian Studies and Services (CASS) sponsors a variety of projects dealing with issues of concern to the Appalachian region. The center's mission is to (1) support scholarly research and artistic endeavors that focus on Appalachia; (2) improve research about the Appalachian region by providing information storage and retrieval systems, educational materials, publications, and media productions; (3) develop educational activities to enhance the intellectual, cultural, social, and economic condition of the region; and (4) provide programs of community outreach and public service, particularly in cul-

tural analysis, esthetic and heritage education, rural health, and public policy.

The Archives of Appalachia preserves and provides access to records of historical and research value pertaining to the political, social, economic, and cultural development of the southern mountains. The Carroll Reece Museum supports research, artistic creativity, and educational activities, including *Artsploration*, a program designed to instruct elementary school children in artistic techniques. CASS publishes *Now and Then*, which presents interviews, essays, short stories, and poems that provide insight into Appalachian life as well as explores Appalachian issues. The center administers a fellowship program that supports research and publications with a regional focus. Funded projects have included critical histories of literature, a radio series, photographic studies, and exhibits. CASS also collaborates with the Department of Sociology and Anthropology at East Tennessee State University to administer an Appalachian studies curriculum.

University of Kentucky
Appalachian Center
641 South Limestone
Lexington, Kentucky 40506-0333
(606) 257-4852

The Appalachian Center at the University of Kentucky focuses on public policy, teaching, research, and service. The center promotes leadership development through workshops and ongoing programs, sponsors an annual conference that brings together community leaders and academics to address key regional issues, and publishes conference proceedings. Through the university, the center offers courses in Appalachian studies and sponsors workshops on topics geared especially for scholars, teachers, and community members. Within the university library, the Appalachian collection contains books and periodicals as well as archival and audiovisual materials on Appalachia. Funding permitting, the center publishes a newsletter twice a year, covering center activities.

Private-Sector Resources

Appalachian Studies Association
c/o Center for Appalachian Studies and Services
East Tennessee State University
Box 70556
Johnson City, Tennessee 37614-0556
(615) 929-5348

Established in 1977, the Appalachian Studies Association (ASA) is an organization of approximately 2,000 scholars, teachers, and regional activists interested in all aspects of Appalachia. The majority of members are interested in history, literature, and sociology. However, association members are showing increased interest in health care issues and community problems. ASA encourages communication among government organizations, grassroots communities, the media, and academia. Recent initiatives include fostering a positive profile of the Appalachian region and involving the region's youth in the association. ASA sponsors an annual Appalachian studies conference, usually attended by 400 to 500 people. Conference sessions focus on Appalachian history, politics, and culture as well as topics such as community organizing, public policy, social reform, and the environment. ASA also sponsors an Appalachian Youth Conference, which meets concurrently with the annual meeting. In addition, the association distributes the newsletter *Appalink* and the *Journal of Appalachian Studies*, which publishes selected papers from the Appalachian studies conference.

Commission on Religion in Appalachia
P.O. Box 10867
Knoxville, Tennessee 37939-0867
(615) 584-6133

The Commission on Religion in Appalachia (CORA) is a regional strategy of church cooperation and community partnership. Since 1965, more than 15 national denominations have come together through CORA to address Appalachian needs. CORA's work focuses on the causes of Appalachia's problems rather than on the symptoms. Empowerment activities include supporting fair employment practices and land ownership/taxing policies, highlighting the struggles of women and minorities, and supporting issue advocacy groups and locally directed cooperatives working for institutional change and economic alternatives. CORA's work is carried out by the Appalachian Development Projects Committee (ADPC), which provides support to approximately 50 locally controlled community-based organizations, Cooperative Congregational Development (CCD), the Northern Appalachian Committee (NAC), the Public Policy and Political Action Strategy Team, and the Volunteer Program. A variety of resource materials are available, including the quarterly newsletter, The *CORAspondent*.

3. Cancer

Federal Resources

American Stop Smoking Intervention Study for Cancer Prevention
Program Director
National Cancer Institute
9000 Rockville Pike, EPN 241
Bethesda, Maryland 20892
(301) 496-0273

The American Stop Smoking Intervention Study for Cancer Prevention (ASSIST) is a collaborative effort between the National Cancer Institute (NCI) and the American Cancer Society, along with state and local health departments and other voluntary organizations. ASSIST is developing comprehensive tobacco control programs in 17 states. The purpose of this intervention is to demonstrate that the widespread, coordinated application of the best available strategies to prevent and control tobacco use will accelerate the downward trend in smoking and other tobacco use significantly, resulting in a substantial reduction in the number and rate of tobacco-related cancers in the United States. ASSIST is a community-based intervention directed by state and local voluntary coalitions that seek to mobilize and activate community resources for smoking prevention and cessation by planning and implementing tobacco control activities. Through ASSIST, media, policy, and cessation support is delivered to target groups using the health care system, schools, worksites, and other community channels. Specific interventions include training health care providers to deliver brief cessation counseling, implementing smoke-free policies in schools and worksites, and enhancing media coverage of tobacco use issues. The program provides an opportunity for resource sharing with the ALIC projects and coalitions. ASSIST has projects and well-established contacts in the following Appalachian states: New York, North Carolina, South Carolina, Virginia, and West Virginia.

Information on how to contact these ASSIST projects is available from the ASSIST program director at the address listed above.

Cancer Information Service
1-(800) 4-CANCER

The Cancer Information Service (CIS) is a nationwide network of 19 regional field offices supported by the National Cancer Institute. Each office provides state-of-the-science information on cancer and support for community outreach activities. The toll-free telephone service connects callers with trained staff members who can provide accurate and up-to-date information on cancer to patients and their families, health professionals, and the general public. CIS offices also serve as NCI's primary outreach network, with CIS outreach staff providing direction, materials, and technical assistance to other NCI-supported programs. CIS can provide the following support and assistance to local programs:

- Information and referrals to community resources, including cancer support groups and smoking and other tobacco use prevention and cessation programs as well as screening, hospice, home health care, and transportation services;
- Promotion of and referrals to local programs and services;
- Assistance with program planning, including help with identifying appropriate outreach strategies, messages, materials, and other resources to reach specific target populations;
- Identification and provision of appropriate NCI educational materials for use in local programs and activities, including materials for specific target audiences such as older Americans and audiences with low reading levels;
- Assistance with media placement, including suggestions concerning appropriate media outlets and introductions to local media contacts;
- Identification of health professionals and other individuals who can serve as appropriate spokespersons on specific health issues as well as materials to assist in training local program staff or volunteers to serve as spokespersons;
- Identification of key intermediaries in specific regions and participation on coalition boards to provide information and assistance in planning local activities; and
- Assistance in using NCI materials for training staff, volunteers, and intermediary networks to conduct education programs in communities.

In addition to materials on cancer, CIS distributes Making Health Communications Work: A Planner's Guide, which discusses the key principles of six specific steps in program development: planning and selecting strategy, selecting channels and materials, developing and pretesting materials, implementing the program, assessing effectiveness, and using feedback to refine the program. The suggestions contained in the guide are based on lessons learned by NCI's Office of Cancer Communications, which develops communication messages for health professionals, patients, and the public.

Below is a list of key contacts for CIS regional offices serving ALIC project areas.

Region 3 (serving New York, Western Pennsylvania)
CIS Outreach Coordinator
Roswell Park
Research Study Center
4th Floor, Room 430
Elm and Carlton Streets
Buffalo, New York 14263
(716) 845-6793

Region 4 (serving Eastern Pennsylvania)
CIS Outreach Coordinator
Fox Chase Cancer Center
Cancer Information Service
510 Township Line Road
Cheltenham, Pennsylvania 19012
(215) 379-1360

Region 5 (serving Maryland)
CIS Outreach Coordinator
Johns Hopkins University
Cancer Information Service
550 North Broadway, Room 307
Baltimore, Maryland 21205
(410) 955-3636

Region 6 (serving Georgia, North Carolina, South Carolina)
CIS Outreach Coordinator
Duke Comprehensive Cancer Center
Duke Cancer Information Service
Erwin Square, Suite 201
2020 West Main Street
Durham, North Carolina 27705
(919) 286-5837

Region 9 (serving Kentucky, Tennessee)
CIS Outreach Coordinator
Markey Cancer Center
Kentucky Cancer Information Service
University of Kentucky
305 Davis-Mills Building MRISC/MCC
800 Rose Street/UKMC
Lexington, Kentucky 40536-0098
(606) 257-4447

Region 10 (serving Southern Virginia)
CIS Outreach Coordinator
Mary Babb Randolph Cancer Center
Cancer Information and Education
Robert Byrd Health Sciences Center of West Virginia University
West Virginia University
P.O. Box 9350
Morgantown, West Virginia 26506-9350
(304) 599-1496

Community Clinical Oncology Program
Program Director
National Cancer Institute
9000 Rockville Pike, EPN 300D
Bethesda, Maryland 20892
(301) 496-8541

The Community Clinical Oncology Program (CCOP) was established by NCI in 1983. Through this program, community physicians work with university physicians and scientists conducting NCI-approved clinical trials to answer specific questions about the effectiveness of new ways to prevent, detect, diagnose, and treat cancer. CCOP helps transfer the latest research findings to the community level and gives more patients and physicians the opportunity to participate in clinical trials. CCOP has established a network of cancer specialists, surgeons, and primary care physicians practicing in community settings. A minority-based CCOP also includes university hospitals that serve a large minority population. Individuals or patients at risk for cancer can be referred to CCOP physicians and hospitals for inclusion in NCI clinical trials. Information on support care also can be provided.

The Minority-Based Community Clinical Oncology Program (MBCCOP) supports participation of minority populations and their physicians in clinical trials, providing access to advances in diagnosis, treatment, and cancer prevention and control to minority patients and opportunities for studies in selected high-risk minority populations.

Below is a list of contacts for CCOP and MBCCOP projects in ALIC Appalachian states.

University of South Alabama MBCCOP
USA Cancer Center
307 University Boulevard, Room 414
Mobile, Alabama 36688
Marcel E. Conrad, M.D.
(205) 633-4246

Atlanta Regional CCOP
Oncology Research Department
St. Joseph's Hospital
5665 Peachtree Dunwoody Road, N.E.
Atlanta, Georgia 30342-1701
Ernest W. Franklin, M.D., (404) 252-9639
Pat Hammond, R.N., (404) 851-7119

Grady MBCCOP
Grady Memorial Hospital
P.O. Box 26042
Atlanta, Georgia 30335-3801
Melvin R. Moore, M.D.
(404) 616-4885

Southeast Cancer Control Consortium CCOP
2150 Country Club Road, Suite 200
Winston-Salem, North Carolina 27104-4241
James N. Atkins, M.D., (919) 777-3036
Katherine Dale, (919) 777-3037

Columbus CCOP
1151 South High Street
Columbus, Ohio 43206
Leslie R. Laufman, M.D., (614) 846-0044
Judy Miller, (614) 443-2267

Dayton Clinical Oncology Program
Cox Heart Institute
3525 Southern Boulevard
Kettering, Ohio 45429
Howard M. Gross, M.D., (513) 296-7278
Nancy A. Hines, R.N., (513) 296-7278

Toledo Community Hospital Oncology Program
3314 Collingwood Boulevard
Toledo, Ohio 43610
Paul L. Schaefer, M.D., (419) 255-5433
Diana J. Frie, Ph.D., CHES, (419) 255-5433

Allegheny CCOP
Allegheny-Singer Research Institute
320 East North Avenue
Pittsburgh, Pennsylvania 15212-9986
Reginald P. Pugh, M.D., (412) 359-3630
Kathleen Russo, R.N., (412) 359-5256

Geisinger Clinical Oncology Program
Department of Hematology/Oncology
Geisinger Medical Center, 20-01
North Academy Avenue
Danville, Pennsylvania 17822
Albert M. Bernath, M.D., (717) 271-6413
Patricia A. Porter, R.N., (717) 271-6413

Mercy Hospital CCOP
General Services Building
746 Jefferson Avenue, Suite 205
Scranton, Pennsylvania 18501
William J. Heim, M.D., (717) 342-3675
Joseph Kishel, (717) 348-7648

Spartansburg CCOP
Spartansburg Regional Medical Center
101 East Wood Street
Spartansburg, South Carolina 29303
James Bearden, M.D., (803) 560-6812
Pam Williams, R.N., M.S.N, O.C.N.,
Oncology Research Department,
(803) 560-6912

MCV/CMH MBCCOP of Virginia
Massey Cancer Center
MCV Station, Box 230
Richmond, Virginia 23298
Christopher Desch, M.D.
(804) 786-0450

Fairfax Community Clinical Oncology Program
Fairfax Hospital
c/o Fairfax Hematology/Oncology
3301 Woodburn Road, #206
Annandale, Virginia 22003
Nicholas J. Robert, M.D., (703) 698-3582
Marilyn Congo, (703) 698-2302

Information on how to contact these CCOP offices is available from the program director at the address listed above.

Comprehensive and Clinical Cancer Centers
(Supported by the National Cancer Institute)
Program Director
National Cancer Institute
9000 Rockville Pike, EPN 502
Rockville, Maryland 20892
(301) 496-8531

NCI-designated cancer centers constitute a national network that provides information on cancer prevention, early detection, diagnosis, treatment, rehabilitation, and long-term needs of survivors and family members. Many of these centers disseminate information by working directly with Cancer Information Service (CIS) offices or by organizing public information services modeled on CIS. Centers designated as comprehensive cancer centers by NCI also conduct outreach efforts in the communities they serve. Information services may include conducting patient education programs to provide current information on local and national resources that serve cancer patients and their families.

The following states in the Appalachian region have comprehensive and clinical cancer centers supported by NCI: Alabama, Maryland,

New York, North Carolina, Ohio, Pennsylvania, Tennessee, and Virginia.

Information on how to contact the offices of these comprehensive and clinical cancer centers is available from the program director at the address listed above.

Data-Based Intervention Research Program
Program Director
National Cancer Institute 9000 Rockville Pike, EPN 233
Bethesda, Maryland 20892
(301) 496-8584

The purpose of the Data-Based Intervention Research (DBIR) Program is to stimulate the development of statewide cancer prevention and control intervention programs based on a thorough appraisal and analysis of a variety of existing local data sources. Projects are responsible for developing a cancer prevention and control plan, testing selected interventions, gathering state support for future cancer prevention and control activities, and evaluating these efforts. Cooperative agreements supported by this program address at least four NCI cancer prevention and control priorities, such as the cessation and prevention of tobacco use, the detection of cervical and breast cancers, and diet modification. NCI is providing support for data analysis, development of a state cancer prevention and control plan, limited intervention implementation based on data analyses and health department priorities, and outcome evaluation. The DBIR Program can provide callers with its current program information. It also can share information on cancer prevention and control planning efforts, offering insight into methods that proved successful for the DBIR Program. Information on legislation also can be obtained from the DBIR state cancer legislation database.

The following states in the Appalachian region are receiving funds from the DBIR Program: Georgia, Kentucky, Maryland, North Carolina, Pennsylvania, and Ohio.

Information on how to contact the offices of these projects is available from the program director at the address listed above.

5-A-Day for Better Health Program
Program Director
National Cancer Institute
9000 Rockville Pike, EPN 330
Rockville, Maryland 20892
(301) 496-8520

The 5-A-Day for Better Health Program is the first nationwide health promotion program to focus on the positive role of fruits and vegetables in reducing the risk of cancer and other chronic diseases. The program is designed to be an active partnership between the National Cancer Institute, the fruit and vegetable industry (represented by the Produce for Better Health Foundation), and the health community. The program's goal is to increase the per capita fruit and vegetable consumption to five or more servings per day by the year 2000. Community interventions include research grants for designing and evaluating 5-A-Day interventions in channels targeting worksites, schools, churches, and low-income food assistance programs. In addition, state health agencies can become licensed participants in the program, providing statewide leadership and coordination for the program.

The following states in the Appalachian region have 5-A-Day for Better Health projects: Alabama, Georgia, Kentucky, Maryland, New York, North Carolina, South Carolina, Pennsylvania, Virginia, and West Virginia.

Information on how to contact the offices of these projects is available from the program director at the address listed above.

The National Black Leadership Initiative on Cancer
NBLIC Program Director
National Cancer Institute
9000 Rockville Pike, EPN 240
Bethesda, Maryland 20892
(301) 496-8589

The National Black Leadership Initiative on Cancer (NBLIC) is the National Cancer Institute's formal outreach initiative to establish a national system to increase cancer prevention and control activities in African-American communities.

National Health Information Center
Office of Disease Prevention and Health Promotion
P.O. Box 1133
Washington, D.C. 20013-1133
(301) 565-4020 or (800) 336-4797

The Office of Disease Prevention and Health Promotion operates the National Health Information Center (NHIC), formerly the National Health Information Clearinghouse. Although NHIC does not answer specific med-

ical questions, it provides reference support to both professionals and the general public through the identification of health information resources, an information and referral system, and publication distribution. For example, it provides patients and family members with the names, addresses, and telephone numbers of organizations that can reply directly to their questions about cancer and other health issues. The center's in-house database is a directory of more than 1,000 health-related organizations that can provide health information. The database is publicly accessible through the National Library of Medicine's online database system, MEDLARS, on the DIRLINE file. The center also maintains a collection of health and medical reference materials, journals, and newsletters that is available to the public by appointment. Several publications are available from the center, including directories, resource guides, and bibliographies on a range of topics such as nutrition, community health promotion programs, family health information resources, health care financing, and special concerns of the elderly and minority populations. A publications list is available. There is a handling fee for most publications.

National Hispanic Leadership Initiative on Cancer
NHLIC Program Director
National Cancer Institute
9000 Rockville Pike, EPN 240
Bethesda, Maryland 20892
(301) 496-8589

The National Hispanic Leadership Initiative on Cancer (NHLIC) is the National Cancer Institute's formal outreach initiative to establish a national system to increase prevention and control activities in Hispanic communities.

Physician Data Query
(800) 4-CANCER

The National Cancer Institute developed this clinically-oriented computer database to make information on cancer treatment widely available to the medical community and to the public. It provides state-of-the-science cancer treatment information, cancer research protocols, and directories of physicians, organizations, and institutions involved in cancer care. Cancer patients, their families, and the public can get easy-to-understand information from Physician Data Query (PDQ) by calling the Cancer Information Service at the toll-free number shown above. Doctors can call CIS for a free first search and information on how to access PDQ on a regular basis by using an office computer, a fax machine, or a medical library with computer access to the database.

Surveillance, Epidemiology, and End Results Program
Cancer Statistics Branch
9000 Rockville Pike, EPN 343J
Bethesda, Maryland 20892
(301) 496-8510

The Surveillance, Epidemiology, and End Results (SEER) Program, a continuing NCI program, collects cancer data on a routine basis from designated population-based cancer registries in various areas of the country. Trends in cancer incidence, mortality, and patient survival in the United States as well as many other studies are derived from this data bank. The goals of the SEER Program are:

- To assemble and report, on a periodic basis, estimates of cancer incidence and mortality in the United States;
- To monitor annual cancer incidence trends to identify unusual changes in specific forms of cancer occurring in population subgroups defined by geographic, demographic, and social characteristics;
- To provide continuing information on changes over time in the extent of disease at diagnosis, trends in therapy, and associated changes in patient survival; and
- To promote studies designed to identify factors amenable to cancer prevention and control interventions such as environmental, occupational, socioeconomic, dietary, and other health-related exposures; screening practices, early detection, and treatment; and determinants of the length and quality of patient survival.

Periodic publications on incidence, mortality, and survival as well as a public-use tape containing the SEER database can be obtained from the address listed above.

Private-Sector Resources

American Cancer Society
National Headquarters
1559 Clifton Road, N.E.
Atlanta, Georgia 30329
(800) ACS-2345 or (404) 320-3333

The American Cancer Society (ACS) is a voluntary health organization that provides services such as information and publications, counseling and guidance, referral to community health services and resources, equipment loans, and rehabilitation programs. ACS offers referral to ACS programs, support groups, and other community resources as well as information on cancer, its treatment, and the care of cancer patients. Many local units also sponsor mutual support programs for cancer patients. Rehabilitation and support programs administered by ACS include "I Can Cope", an 8-week patient education program assisting patients and their families; Reach to Recovery, which provides rehabilitation support for women who have had breast cancer; and "Look Good . . . Feel Better", which offers information and guidance to help cancer patients undergoing chemotherapy and radiation treatment. ACS also offers public education programs for youth and adults on prevention and risk reduction as well as early detection. ACS offices also may be able to lend equipment such as beds, walkers, and wheelchairs for use in the home; provide limited financial assistance to medically needy cancer patients for pain and nausea medications; and arrange for transportation to and from treatment. ACS recently completed three demonstration projects on community cancer detection, education, and prevention for socioeconomically disadvantaged populations in Harlem (New York City), Miami, and west Oakland (California). All states located in the Appalachian region have chartered divisions of ACS.

Central Pennsylvania Oncology Group
Milton S. Hershey Medical Center
Pennsylvania State University
P.O. Box 850
Hershey, Pennsylvania 17033
(717) 531-8341

The Central Pennsylvania Oncology Group (CPOG) was formed in 1974 with an initial goal of developing and testing new treatment regimens through the use of rigorously designed research studies. This allowed physicians in a 34-county, mostly rural, area of Pennsylvania to participate directly in planning and testing treatment protocols, making the studies available to patients in their own community hospitals. CPOG also has expanded its efforts into education and service programs for medical professionals interested in the treatment of cancer. During 1986, CPOG began a community outreach program in cancer awareness and prevention that has reached thousands of central Pennsylvanians in their own communities successfully. The goals of this 200-member group are to:

- ► Improve the quality of cancer patient care;
- ► Conduct studies on the effectiveness of cancer treatment regimens with protocols developed and evaluated by CPOG;
- ► Improve communications and coordination of cancer treatment in central Pennsylvania;
- ► Educate CPOG members and the medical community at large in newer aspects of cancer treatment; and
- ► Educate the general public in central Pennsylvania regarding cancer awareness, prevention and control, and early detection.

National Alliance of Breast Cancer Organizations
1180 Avenue of the Americas, Second Floor
New York, New York 10036
(212) 719-0154

The National Alliance of Breast Cancer Organizations (NABCO) fosters cooperation among organizations and individuals involved in efforts to combat breast cancer. It also serves as a resource for persons who are concerned about breast cancer and other breast diseases. NABCO also seeks to affect public and private policy in areas such as national, state, and local legislation; funding priorities; and insurance reimbursements. NABCO prefers written inquiries.

National Coalition for Cancer Survivorship
1010 Wayne Avenue, 5th Floor
Silver Spring, Maryland 20910
(301) 650-8868

The National Coalition for Cancer Survivorship (NCCS) is a consumer-oriented network that links independent organizations, hospitals, cancer centers, and individuals who are concerned with survivorship and the mutual support for cancer survivors and their loved ones. NCCS's primary goal is to promote a national awareness of issues affecting cancer survivors. It provides information on sources of support for cancer patients and their families, holds an annual conference on survivorship issues, advocates for the legal rights of cancer survivors, and provides technical assistance to

community cancer organizations. The coalition also publishes a national newsletter and other materials that help cancer survivors locate resources, communicate with their health care team, and deal with issues such as job and insurance discrimination. NCCS encourages outreach to underserved survivor populations and is dedicated to expanding peer support resources to address the needs of men and women from all economic and social backgrounds.

4. Rural Health

Federal Resources

Agency for Health Care Policy and Research Publications Clearinghouse
P.O. Box 8547
Silver Spring, Maryland 20907-8547
(301) 495-3453 or (800) 358-9295

Formerly the National Center for Health Services Research and Health Care Technology Assessment, the Agency for Health Care Policy and Research (AHCPR) was established in 1989 as a separate Public Health Service agency. As the leader of federal efforts in outcome research and health services research, AHCPR seeks to create and disseminate new knowledge and better understanding of the new processes by which health services are made available and how they can be provided more efficiently and effectively. The agency conducts and supports scientific research targeted to the needs of health care policymakers at the federal, state, and local levels; those who operate hospitals and other health care institutions; and individuals who are responsible for health care expenditures. Research findings are disseminated through publications, conferences, and workshops. A major component of AHCPR's research program is the National Medical Expenditure Survey, which provides current information on how much Americans use, pay for, and finance medical care. AHCPR also is developing clinical practice guidelines designed to assist practitioners in the prevention, diagnosis, treatment, and management of clinical conditions. Publications on rural health include an annotated bibliography on rural health services research; *Delivering Essential Health Care Services in Rural Areas: An Analysis of Alternative Models;* and *Rural Health Care: The Future of the Hospital.* Materials also are available on health care costs, utilization, expenditures, health information systems, and health technology assessment. The monthly publication, *AHCPR Research Activities*, summarizes key research findings and announces the availability of new reports. Most publications are available from the AHCPR Publications Clearinghouse (see above).

Area Health Education Centers
Program Director
Health Resources and Services Administration
5600 Fishers Lane, Room 4C05
Rockville, Maryland 20857
(301) 443-6950

Area Health Education Centers (AHECs) are funded by the Bureau of Health Professionals, Health Resources and Services Administration (HRSA), through cooperative agreements with major institutions that subcontract work to several smaller centers. The purpose of this support is to attract and retain primary care professionals in primary medical care Health Professional Shortage Areas by linking academic science centers with clinical sites in underserved urban and rural communities. Centers receive funding to establish networks of health-related institutions to provide educational services to students, faculty, and practitioners. AHECs encourage project-to-project interaction and can provide lists of resources as well as contact persons.

The following states in the Appalachian region have AHECs: Georgia, Kentucky, Maryland, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Virginia, and West Virginia.

Information on how to contact AHECs in these states is available from the program director at the address listed above.

Community Health Centers Program Director
Health Resources and Services Administration
5600 Fishers Lane
Rockville, Maryland 20857
(301) 443-2260

Community health centers (CHCs) were first funded by the federal government as part of the "War on Poverty" in the mid-1960s. Consumer participation was mandated, and this commitment continues today with each center required to have a governing board composed of a majority of users of its services. The Public Health Service currently has responsibility for directing the Community Health Center Program. Approximately 550 public and private nonprofit organizations receive community health center grants to operate about 1,400 clinics. More than half are located in rural areas. CHCs provide

family-oriented, culturally sensitive primary care services to medically underserved populations. They also provide laboratory tests, x-rays, and pharmacy services. Some CHCs complement these services with preventive health care, dental services, and a variety of community services such as transportation, health education, long-term care, and mental health services. The program can provide more information about CHCs and local CHC services.

Center on Aging and Health in Rural America (CAHRA)
601 Oswald Tower
Pennsylvania State University
University Park, Pennsylvania 16802
(814) 863-2938

Funded by the National Institute on Aging, the Center on Aging and Health in Rural America (CAHRA) was founded in September 1990 to stimulate interdisciplinary research on issues related to the health and effective functioning of local rural Americans. A major goal of CAHRA has been to encourage researchers who already conduct research in health and aging to add a meaningful rural component to their work. In addition, Pennsylvania State University has a long research tradition in the area of rural population; CAHRA has successfully encouraged some of these scholars to add dimensions of health and aging to their rural research programs.

Office of Rural Health Policy
Parklawn Building, Room 9-05
5600 Fishers Lane
Rockville, Maryland 20857
(301) 443-0835

The Office of Rural Health Policy (ORHP) was established within the U.S. Department of Health and Human Services in fall 1987. The major responsibility of this office is to work within the department and with other federal agencies, states, national associations, foundations, and private-sector organizations to identify and seek solutions to health care problems in rural communities. The office administers the Rural Health Research Center grant program, which supports university-based research centers in the collection and analysis of information, the conduct of applied research on rural health, and the dissemination of the results. As the major federal coordinator for rural health, ORHP works closely with the National Rural Health Association and supports a number of important small community grants. It is a good source of current information on all aspects of rural health, including state-level rural health legislation, health status and health care services, and medicare and medicaid beneficiaries.

National Clearinghouse for Primary Care Information
8201 Greensboro Drive, Suite 600
McLean, Virginia 22102
(703) 821-8955

Established in 1983, the National Clearinghouse for Primary Care Information (NCPCI) is funded through HRSA's Bureau of Primary Health Care, Division of Community Migrant Health. The clearinghouse provides information services to support planning, development, and delivery of ambulatory health care to urban and rural areas that have shortages of medical personnel and services. The clearinghouse distributes publications focusing on ambulatory care, financial management, primary health care, and health services administration. Although NCPCI responds to requests from the general public, its primary audience is health care practitioners and administrators.

Rural Information Center
Health Services Section
National Agricultural Library
10301 Baltimore Boulevard, Room 304
Beltsville, Maryland 20705-2351
(301) 344-2547 or (800) 633-7701

The Rural Information Center is located at the U.S. Department of Agriculture's National Agricultural Library, which houses the Agricultural Library Forum (ALF), an electronic bulletin board that allows users to access and share information. ALF can be used to network with colleagues and to learn about upcoming conferences and new grant opportunities. The Rural Information Center maintains a section on ALF that includes information on rural health and development. Bulletin board topics include publications relevant to rural health, reports from Rural Health Research Centers, foundations supporting rural health, and federal legislation on rural health issues. The Health Services section of the center can conduct online database searches of literature on rural health and can provide publications on agricultural safety and health, health care and the elderly in rural America, and a resource guide on rural health services funding. Other publications dis-

tributed by the center address rural leadership, public decisions, and community change; economic development; local government; and the quality of rural life and natural resources.

State Resources

State Offices of Rural Health

Offices of Rural Health have been established by states to be focal points for rural health activities, including the coordination, advocacy, planning, administration, and evaluation of rural health activities at the state level.

Listed below are the Offices of Rural Health of states located in the Appalachian region.

Alabama
Office of Rural Health
Office of the Governor
125 Ripley Street, Suite 1
Montgomery, Alabama 36104
(205) 242-3439

Georgia
Office of Rural Health
Division of Public Health
Georgia Department of Human Resources
878 Peachtree Street, N.E., Suite 100
Atlanta, Georgia 30309-9844
(404) 894-4283

Kentucky
Center for Rural Health
University of Kentucky
100 Airport Gardens Road, Suite 10
Hazard, Kentucky 41701
(606) 439-3557

Maryland
Office of Rural Health
Maryland Department of Health and Mental Hygiene
201 West Preston Street, Room 225
Baltimore, Maryland 21201
(410) 225-5806

Mississippi
Office of Rural Health
Mississippi State Department of Health
P.O. Box 1700
2324 North State Street
Jackson, Mississippi 39215-1700
(601) 960-7874

New York
Office of Rural Health
Bureau of Health Planning Policy Development
New York Department of Health
Corning Tower, Room 1656
Empire State Plaza
Albany, New York 12237
(518) 474-5565

North Carolina
Office of Rural Health and Resource Development
North Carolina Department of Human Resources
311 Ashe Avenue
Raleigh, North Carolina 27606
(919) 733-2040

Ohio
Office of Primary Care and Planning
Ohio Department of Health
246 North High Street
Columbus, Ohio 43266-0118
(614) 644-8508

Pennsylvania
Office of Rural Health
Department of Agricultural Economics and Rural Sociology
Pennsylvania State University
2 Weaver Building
University Park, Pennsylvania 16802
(814) 863-8214

South Carolina
Office of Rural Health, Migrant Health and Primary Care
South Carolina Department of Health
2600 Bull Street
Columbia, South Carolina 29201
803) 737-3995

Tennessee
Office of Rural Health
Tennessee Department of Health
536 Cordell Hall Building
Nashville, Tennessee 37247-5410
(615) 741-7308

Virginia
Center for Rural Health
Virginia Department of Health
1500 East Main Street, Room 213
Richmond, Virginia 23219
(804) 786-6970

West Virginia
Office of Rural Health Policy
West Virginia Department of Health
1411 Virginia Street, East
Charleston, West Virginia 25301
(304) 558-3210

Private-Sector Resources

National Rural Health Association
National Headquarters
1320 19th Street, N.W., Suite 350
Washington, D.C. 20036-1610
(202) 232-6200

National Service Center
One West Armour Boulevard, Suite 301
Kansas City, Missouri 64111
(816) 756-3140

The National Rural Health Association (NRHA) is a not-for-profit association composed of individuals and organization members who share a common interest in rural health. Members include administrators, researchers, government workers, and physicians and other private practice health professionals as well as hospitals, community and migrant health centers, and government and education institutions. NRHA sponsors an Annual Conference on Rural Health as well as a Rural Health Policy Institute, which gives members an opportunity to become directly involved in the federal legislative process. The association publishes the quarterly *Journal of Rural Health*, which serves as a medium for communication among health professionals and scientists on research, policy, educational opportunities, and practice applications. The association's bimonthly newsletter, *Rural Health Care*, disseminates news and information of interest to rural health professionals with the goal of establishing a network of rural health advocates. NRHA recently published *National Health Policy Reform: The Rural Perspective*, a document detailing the association's study of issues pertaining to national health care reform. Among other NRHA publications are a list of rural health care projects funded by foundations; a rural health resources directory; a monograph series on survival strategies for rural hospitals; and reports on topics such as the Rural Health Clinic Services Act, innovations in rural health care delivery, and rural emergency medical services.

5. Coalitions, Community Development, and Health Education

Federal Resources

Northeast Regional Center for Rural Development
7 Armsby Building
Pennsylvania State University
University Park, Pennsylvania 16802
(814) 863-4656

In the early 1970s and in response to an initiative by the Cooperative State Research Service, U.S. Department of Agriculture, the land grant system established four regional centers to coordinate rural development. Located at Pennsylvania State University, the Northeast Regional Center for Rural Development is concerned with the causes and consequences of social, political, cultural, and economic changes in rural areas and the effective adaptation of rural people, businesses, and communities to those changes. The center initiates and facilitates efforts through networks of scientists from a variety of disciplines who identify important research and educational issues and then develop strategies for dealing with those issues to improve the social and economic well-being of nonmetropolitan communities in the nation. The center also provides supplemental research and extension funds and programs through seed money grants.

Planned Approach to Community Health
Centers for Disease Control and Prevention
4770 Beford Highway, N.E., MS K-46 Atlanta,
Georgia 30341-3724
(404) 488-5426

The Centers for Disease Control and Prevention (CDC) administers the Planned Approach to Community Health (PATCH), a process that involves and enables members of a community to plan, implement, and evaluate programs designed to reduce the burden of disease in their communities. *PATCH: Local Coordinator's Guide* includes chapters on mobilizing communities; collecting and organizing data; choosing priority problems, target groups, and types of interventions; and performing process and outcome evaluations. Program descriptions of PATCH projects and training workshops on the PATCH process for state health department staff are also available. Local groups can contact their state health

departments for technical assistance, training, and materials pertaining to community PATCH projects.

The following states located in the Appalachian region have state and local PATCH coordinators: Alabama, Ohio, South Carolina, and West Virginia.

Information on how to contact the PATCH coordinators in these states is available at the address listed above.

National Clearinghouse for Alcohol and Drug Information
P.O. Box 2345 6000 Executive Boulevard
Rockville, Maryland 20852
(301) 468-2600 or (800) 729-6686

The National Clearinghouse for Alcohol and Drug Information distributes several publications on community-based health programs prepared by the Center for Substance Abuse Prevention (CSAP). Although the primary focus of these materials is on alcohol and other drug abuse prevention, much of the information on program planning and coalition building has general application to health promotion and disease prevention programs. Available guides include *The Future by Design*, which presents a framework for community-based prevention efforts; *Prevention Plus III*, which uses a workbook format to provide practical guidance for conducting process and outcome evaluations; and *Getting It Together*, a guide for helping communities tap the expertise and enthusiasm of young people who have a commitment to improving health in their neighborhoods.

Office of Minority Health Resource Center
P.O. Box 37337
Washington, D.C. 20013-7337
(301) 587-1938 also (800) 444-6472

Established in 1987 by the Public Health Service's Office of Minority Health, the Office of Minority Health Resource Center (OMH-RC) has staff members who are available to answer mail and telephone requests received from consumers and professionals. Information specialists refer requests to appropriate organizations, locate relevant materials, and identify sources of technical assistance. The resource center maintains information on health-related resources available at the federal, state, and local levels that target minority populations. The activities of OMH-RC concentrate on several health priority areas, including cancer and nutrition. OMH-RC has established the Resource Persons Network (RPN), a network of more than 2,000 physicians, nurses, social workers, health educators, and epidemiologists who provide expert technical assistance to community-based organizations, voluntary groups, and individuals. Areas of expertise include building community-based coalitions. The network is based on reciprocity: Individuals may call OMH-RC and be referred to an RPN member, and an RPN member may call the resource center to obtain access to other health professionals.

State Resources

United States Conference of Mayors
1620 Eye Street, N.W.
Washington, D.C. 20006
(202) 293-7330

Founded in 1932, the United States Conference of Mayors (USCM) promotes improved municipal government by cooperation between cities and the federal government and provides education, technical assistance, information, and legislative services to cities. Health is the focus of one of the USCM committees. USCM's Community-Based HIV/AIDS Grant and Technical Assistance Program, also supported by the Centers for Disease Control and Prevention, provides assistance to community-based organizations in applying for grants, grant writing, materials development, and evaluation. Many of the materials developed for, and as a result of, this program provide helpful information for building community-based coalitions focused on other health problems. These publications include case studies of current and past USCM grantees that focused on community-based coalition development. Past topics have included using focus groups to develop education materials. USCM also has developed a series of technical assistance reports that provide how-to information on topics such as event planning, proposal writing, media relations, and evaluation of programs. Technical assistance for developing community-based coalitions is available through USCM's minority health component, which addresses diseases such as cancer and includes a focus on migrant and rural health issues.

Center for Rural Pennsylvania
212 Locust Street, Suite 604
Harrisburg, Pennsylvania 17101
(717) 787-9555

The Center for Rural Pennsylvania was created by the Pennsylvania General Assembly to ensure access by rural and small communities to the problemsolving tools they need for setting their own agenda for a successful future. The center aids rural policy officials and local leaders in the practical implementation of techniques that will serve local goals and create successful communities. The center achieves this through research, policy development, and technical assistance to Pennsylvania's rural region. Activities of the center include:

- ► Grants for research and demonstration projects through the State System of Higher Education Universities and Pennsylvania State University;
- ► Maintaining a database on rural conditions;
- ► Producing publications aimed at sharing project results with policymakers and local leaders;
- ► Sponsoring workshops; and
- ► Promoting state and national policy forums that address rural and small community needs.

The center also serves as a clearinghouse for ideas and programs and maintains an overview of resources for local communities.

Community and Rural Development Institute
Cornell University
48 Warren Hall
Ithaca, New York 14853-7801
(607) 255-9510

The Community and Rural Development Institute (CaRDI) was established in 1990 by Cornell University faculty and staff to:

- ► Increase attention to the special needs of people and communities in New York and the nation by promoting research and policy analysis on community and rural development issues;
- ► Improve the quality of life in rural and urban communities by supporting educational and research programs in economic development, environmental management, human services, and local government; and
- ► Increase collaboration among research and outreach programs at Cornell and serve as a point of entry for policymakers and community leaders interested in linking with Cornell's programs.

CaRDI brings together more than 200 faculty members and research and extension specialists in economic development, environmental management, human services, and institutional leadership to achieve these goals.

Private-Sector Resources

Allegany County (MD) Human Resources Development Commission (HRDC)
Executive Director
19 Frederick Street
Cumberland, Maryland 21502
(301) 777-5970

This organization plans and coordinates programs designed to combat the problems of poverty and seeks the elimination of conditions of poverty as they affect the rural and urban areas of Allegany County. Branch/satellite/field operations include Area Agency on Aging, Adult Day Care Centers, Emergency Funding, Guardianship, Homeless Services Program, Legal Services Program, Maryland Energy Assistance Program, Nutrition Program, Ombudsman Program, Senior Citizen Center, Weatherization Program, Willow Valley Apartments, and Senior Assisted Housing.

Interfaith Consortium, Inc.
209 North Centre Street
Cumberland, Maryland 21502
Executive Director
(301) 777-7388

The purpose of this organization is to provide assistance in the tri-state area for tutoring (Literacy Tutor); supplemental food program (SHIP); housing repair for low-income elderly/disabled persons (HOMAR); a retired seniors volunteer program (RSVP); and a rehabilitation program (Intervention Housing).

To be eligible for these programs, persons must be residents of Allegany/Garrett counties, Maryland; Beford/Somerset counties, Pennsylvania; or Hampshire/Mineral counties, West Virginia. WIC guidelines are followed for for SHIP and Intervention Housing and State of Maryland guidelines for HOMAR.

Highlander Research and Education Center
Executive Director
1959 Highlander Way
New Market, Tennessee 37820
(615) 933-3443

The Highlander Research and Education Center was founded in 1932 to work with grassroots community groups in Appalachia and the South to resolve pressing social problems through collective action. Highlander's history includes education for workers in the 1930s and 1940s, literacy programs for African-American southerners desiring to vote in the 1950s, and assisting local community organizers in the 1960s and 1970s. Current programs address economic and environmental problems as well as leadership and youth development. Program emphasis is on "what ordinary people can achieve." The center sponsors a variety of workshops; distributes a newsletter, *Highlander Reports*; operates a resource center; and produces educational materials.

Mountain Association for Community Economic Development
President
433 Chestnut Street
Berea, Kentucky 40403
(606) 986-2373

The Mountain Association for Community Economic Development (MACED) started in 1976 as a private nonprofit organization when local groups joined together to improve economic conditions and the quality of life in the eastern Kentucky Appalachian Mountains. Today, MACED manages development programs in forestry, education, and local governance as well as an economic development fund of more than $2 million. MACED's philosophy supports an economic process that integrates four elements: "the right thing, the right time, the right people, and the right structure."

National Coalition Building Institute
1835 K Street, N.W., Suite 715
Washington, D.C. 20006
(202) 785-9400

The National Coalition Building Institute (NCBI) is a nonprofit leadership training organization with chapters in 35 cities where local community leaders trained by NCBI work together as a resource team to teach skills in prejudice reduction and conflict resolution. NCBI holds its semiannual Prejudice Reduction Leaders Institutes in April and August and its annual Leadership Training Institute in August of each year. These institutes teach participants the steps involved in developing and leading programs focused on welcoming diversity. *The Art of Coalition Building: A Guide for Community Leaders*, a 46-page how-to manual filled with concrete ideas for building effective intergroup coalitions, is available through NCBI for $10.

The following states located in the Appalachian region have NCBI chapters: Alabama (Birmingham), Georgia (Atlanta), Kentucky (Louisville), Maryland (Baltimore), New York (Upstate), North Carolina (Durham/Chapel Hill), Ohio (Cleveland), Pennsylvania (Lehigh Valley and Susquehanna Valley), Tennessee (Nashville), and Virginia (Harrisonburg).

Information on how to contact NCBI chapters in these states is available at the address listed above.

WQED TV
4802 Fifth Avenue
Pittsburgh, Pennsylvania 15213
(412) 622-1320

WQED TV provides public broadcasting services to southwestern Pennsylvania and parts of Ohio, West Virginia, and Maryland. In addition to quality national and local programming and educational services in partnership with area educational institutions and agencies, a longtime specialty of the station has been community outreach. Outreach projects are developed in partnership with area individuals, agencies, coalitions, and other organizations to raise awareness about critical issues, provide information and materials about the issues, and help inform individuals about what they can do to help effect change or to obtain services themselves. Projects contain some or all of the following: television programming, public service announcements, training videos and teleconferences, print materials (e.g., posters, manuals, leader's guides, flyers), community coalition building or strengthening, events, and promotion. Ideas generally are brought to WQED by individuals and organizations in the community. Subjects vary, but major projects have included teenage drug and alcohol use, illiteracy, breast cancer, prostate cancer, eating disorders, and women's health. Health issues and women's health issues are of particular interest to WQED at present.

Appendix E

Acronyms

ACS: American Cancer Society

ACTWU: Amalgamated Clothing and Textile Workers Union

AHEC: area health education center

ALIC: Appalachia Leadership Initiative on Cancer

ARC: Appalachian Regional Commission

ASSIST: American Stop Smoking Intervention Study for Cancer Prevention

BRFSS: Behavioral Risk Factor Surveillance System

CDC: Centers for Disease Control and Prevention

CES: Cooperative Extension Service

CHALIC: Central Highlands Appalachia Leadership Initiative on Cancer

CHC: community health center

CIS: Cancer Information Service

COMMIT: Community Intervention Trial for Smoking Cessation

COPC: community-oriented primary care

COSSMHO: National Coalition of Hispanic Health and Human Services Organizations

CPOG: Central Pennsylvania Oncology Group

DCC: District Cancer Council

DCPC: Division of Cancer Prevention and Control

EFNEP: Expanded Food and Nutrition Education Program

ES-USDA: Extension System-U.S. Department of Agriculture

ETSU: East Tennessee State University

HPV: Human papilloma virus

HTLV-1: human T-cell lymphotropic virus type 1

KAB: knowledge, attitudes, and behavior

KCP: Kentucky Cancer Program

LDD: local development district

LPM: Lucille Parker Markey

MBRCC: Mary Babb Randolph Cancer Center

MHC: migrant health center

NALIC: Northern Appalachia Leadership Initiative on Cancer

NBCC: National Breast Cancer Coalition

NBLIC: National Black Leadership Initiative on Cancer

NCALIC: North Central Appalachia Leadership Initiative on Cancer

NCHS: National Center for Health Statistics

NCI: National Cancer Institute

NHCCRN: National Hispanic Cancer Control Research Network

NHIS: National Health Interview Survey

NHLIC: National Hispanic Leadership Initiative on Cancer

NHSC: National Health Service Corps

NIH: National Institutes of Health

NOIB: National Outreach Initiatives Branch

OHEI: Office of Health Education and Information

PCI: Pittsburgh Cancer Institute

PDQ: Physician Data Query

PSA: prostate-specific antigen

SALIC: Southern Appalachia Leadership Initiative on Cancer

SEER: Surveillance, Epidemiology, and End Results program

SOCM: Save Our Cumberland Mountains

UAW: United Auto Workers

UMWA: United Mine Workers of America

USDA: U.S. Department of Agriculture

USWA: United Steelworkers of America

VFD: volunteer fire department

WIC: Special Supplemental Food Program for Women, Infants, and Children

Appendix F

Defining Urban and Rural Places

This monograph combines several methods of distinguishing urban and rural counties. The U.S. Department of Agriculture's (USDA) Rural-Urban Continuum Codes, often referred to as Beale Codes, form a classification scheme that distinguishes metropolitan counties by size and nonmetropolitan counties by degree of urbanization or proximity to metropolitan areas (Butler 1990). A list of the USDA's Rural-Urban Continuum Codes associated with each of the 399 Appalachian counties is presented in Appendix A.

To create two urban/rural categories for counties within the ALIC program, the USDA continuum codes were collapsed as follows: Continuum codes 0 through 5 are termed "urban", and codes 6 through 9 are termed "rural". Based on these groups, a rural Appalachian county is defined as a nonmetropolitan county with an urban population of less than 20,000. Table 1 illustrates how the Rural-Urban Continuum Codes are individually defined and then grouped into the urban and rural categories used for the ALIC program and this monograph.

Note

1. The General Accounting Office also has used this definition to identify rural counties (U.S. General Accounting Office 1989).

References

Butler, M.A. *Rural-Urban Continuum Codes for Metro and Nonmetro Counties*. U.S. Department of Agriculture, Economic Research Service, Agriculture and Rural Economy Division. Staff Report No. 9028, April 1990.

U.S. General Accounting Office. *Rural Development: Federal Programs That Focus on Rural America and Its Economic Development*. Briefing report to the Ranking Minority Member, Subcommittee on Conservation, Credit, and Rural Development, Committee on Agriculture, U.S. House of Representatives. GAO/RCED-89-56BR, January 1989, pp. 12-16.

Table 1. ALIC rural and urban county categories based on the USDA Rural-Urban Continuum codes for metro and nonmetro counties

Code	Type of County		Definition
URBAN COUNTIES *(as defined in this monograph)*			
0	Metropolitan Counties	Core large metropolitan	Central counties of metropolitan areas of 1 million population or more
1		Fringe metropolitan	Fringe counties of metropolitan areas of 1 million population or more
2		Medium metropolitan	Counties in metropolitan areas of 250,000 to 1 million population
3		Lesser metropolitan	Counties in metropolitan areas of less than 250,000 population
4	Nonmetropolitan Counties	Urbanized/adjacent	Urban population of 20,000 or more, adjacent to a metropolitan area
5		Urbanized/nonadjacent	Urban population of 20,000 or more, not adjacent to a metropolitan area
RURAL COUNTIES *(as defined in this monograph)*			
6	Nonmetropolitan Counties	Less urbanized/adjacent	Urban population of 2,500 to 19,999, adjacent to a metropolitan area
7		Less urbanized/nonadjacent	Urban population of 2,500 to 19,999, not adjacent to a metropolitan area
8		Completely rural/adjacent	Completely rural or fewer than 2,500 urban population, adjacent to a metropolitan area
9		Completely rural/nonadjacent	Completely rural or fewer than 2,500 urban area population, not adjacent to a metropolitan area.

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Sowing Seeds in the Mountains

This monograph exhibits much work on the part of its contributors to accurately describe the "residents of rural areas of the Appalachian region," who will be served by the Appalachia Leadership Initiative on Cancer. The monograph should be helpful to the people who are involved in the four projects. The conclusion portion of chapter 5, Lessons from Change Efforts in Appalachia, has some particularly good information about structuring successful community-based programs in Appalachia.
Francis E. Moravitz, Executive Director, Appalachian Regional Commission.

...The monograph raises very important issues about coalition building for social change in Appalachia and other poor areas. By implication, it addresses some critical concerns for national health care policy... If, in fact, the ALIC program evolves from the seeds described in this monograph, it will provide a new model of community health enhancement nationwide. Therefore, both the volume and its title are appropriate.
Ron D Eller, Ph.D., Director, Appalachian Center, University of Kentucky.

...This is an impressive and unique piece of work. I am not aware of any similar effort to document the integration of coalition building, cancer prevention, community-based strategies and extended health care service delivery in a monograph that can serve as a planning document, a training manual, and a base line for future reference.
Edward F. Meehan, M.P.H., Executive Director, The Dorothy Rider Pool Health Care Trust, Allentown, Penn.

I thought the chapter on Activists and Advocates was outstanding.
David J. Sencer, M.D., M.P.H., Atlanta, GA.

For me, a major measure of success in a document like this, is whether it keeps my attention and I learn something. In this case, both have occurred. ...I expect this will be a useful resource document that people in the field will find very helpful.
Thomas J. Kean, M.P.H., Deputy Director for Operations, AMC Cancer Research Center.

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